



# Implementing the Resident Assessment Instrument: Case Studies of Policymaking for Long-Term Care in Eight Countries

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## FOREWORD

The authors of these case studies describe the use of unique instruments, devised by cross-national collaborators, to array and assess data about persons who receive long-term care and related services in eight countries. These data are of particular importance for policy to improve the quality of care—either voluntarily or through regulation—and to allocate resources more effectively and efficiently across a continuum of services. The instruments also make it possible to compare the cost and quality of long-term care services in different parts of a country and among countries.

The Milbank Memorial Fund, an endowed philanthropic foundation, collaborates with decision makers in the public and private sectors to develop and implement policy that maintains and improves health. The Fund and its constituents among decision makers are eager to learn about the best evidence available to inform choices among alternative policies.

The federal government in the United States commissioned researchers to design and test the instruments that later became the basis of the international project in order to improve formal regulation of the quality of care. Researchers from 22 countries subsequently devised a family of related instruments and helped to adapt them to conditions in particular countries.

Many people participated in writing and reviewing these case studies. They are identified in the Acknowledgments.

Brant Fries requires special recognition. A founder of *interRAI*, the organization that devised the family of instruments, he was central to planning the case study project and essential to encouraging authors to draft, revise, and revise yet again their manuscripts. Fries and Charles Fahey, a program officer of the Fund, convened a meeting of the authors in Helsinki to review the initial drafts of the cases in the difficult month of September 2001. Fries and Fahey collaborated in writing the introduction to the report, in which they describe the history of the project and the significance of the experience reported in the cases for clinicians and policymakers.

Daniel M. Fox  
President

Samuel L. Milbank  
Chairman

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Sergio Ariño Blasco, Consultant Geriatrician and Director, Health/Social Care Department, Fundació Hospital Asil de Granollers, Barcelona, Spain; Christine E. Bishop, Schneider Institute for Health Policy, Heller Graduate School, Brandeis University, Waltham, Mass.; Charles Botz, London Health Sciences Centre, London, Canada; A.M. Clarfield, Sidonie Hecht Professor of Gerontology, Ben Gurion University of the Negev, Beersheva, Israel; June Crown, London, U.K.; Michael J. Donnelly, Reader, Epidemiology and Public Health, School of Medicine, Queen's University Belfast, Belfast, U.K.; Luigi Ferrucci, Clinical Research Branch, National Institute on Aging, Baltimore, Md., and Laboratory of Clinical Epidemiology, Istituto Nazionale Ricovero e Cura Anziani (INRCA) Geriatric Department, Florence, Italy; Robert B. Friedland, Director, Center on an Aging Society, Georgetown University, Washington, D.C.; A\_alsteinn Gu\_mundsson, Medical Director, Hrafnista-DAS Nursing Homes, Staff Geriatrician, University Hospital of Iceland, Reykjavik, Iceland, and Clinical Assistant Professor, University of Wisconsin Medical School, Madison, Wis.; Jack Habib, Director, JDC-Brookdale Institute of Gerontology and Human Development, Jerusalem, Israel; James K. Haveman, Jr., Director, Michigan Department of Community Health, Lansing, Mich.; Shuichiro Hayashi, Chief, Division of Health for the Elderly, Ministry of Health, Labor, and Welfare, Tokyo, Japan; Miriam J. Hirschfeld, Director, Long-term Care CCL/NMH, World Health Organization, Geneva, Switzerland; Katsunori Kondo, Associate Professor, Faculty of Social Welfare, Nihon Fukushi University, Okuda, Japan; Sandra D. Lang, Deputy Minister, Ontario Ministry of Consumer and Business Services, Toronto, Canada; Ariela Lowenstein, Head, Department of Masters in Gerontology and Center for Research and Study of Aging, Faculty of Welfare and Health Studies, University of Haifa, and Chair, European Behavioral, Social Science and Research Section, International Association of Gerontology—European Region, Haifa, Israel; Niccolò Marchionni, Professor of Gerontology and Geriatric Medicine, Department of Critical Care Medicine and Surgery, University of Florence, Florence, Italy; José M. Martín-Moreño, Director, Spanish Agency for Health Technology Assessment, Institute of Health “Carlos III,” Madrid, Spain; Olivia P. Maynard, President, Michigan Prospect for Renewed Citizenship, and Regent, University of Michigan, Flint, Mich.; David R. Nerenz, Director, Institute for Health Care Studies, Michigan State University, East Lansing, Mich.; Stuart G. Parker, Clinical Director, Sheffield Institute for Studies on Aging, University of Sheffield, Sheffield, U.K.; Susan Reinhard, Co-Director, Center for State Health Policy, Rutgers University, New Brunswick, N.J.; William E. Reynolds, Public Service Professor, School of Social Welfare, and Clinical Associate Professor, School of Public Health, State University at Albany, Albany, N.Y.; Otto Christian Rø, Project Manager, Norwegian Board of Health, Oslo, Norway; Leocadio Rodríguez-Mañas, Geriatric Service, Hospital Universitario de Getafe, and Spanish Geriatric Medicine Society, Madrid, Spain; Maria Pilar Salinas Bujan, Regional Manager for Elderly Care, Health/Social Services Coordination Program, Galician Ministry of Health, Santiago de Compostela, Spain; Martin W. Shreeve, Programme Director, Better Government for Vulnerable People, Wolverhampton, U.K.;

Sigurveig H. Sigurdardóttir, Director, Iceland Red Cross, Reykjavik branch, Reykjavik, Iceland;  
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**INTRODUCTION: LESSONS LEARNED FROM EIGHT CASE STUDIES**  
by Brant E. Fries and Charles J. Fahey

The case studies presented in this report tell the stories of researchers and their policy colleagues from eight countries who are committed to the concept that collecting accurate information in a common format within and across service sectors and countries enhances both the well-being of frail persons and the efficient and the equitable distribution of public resources. The cases are the work of researchers who in 1992 formed a nonprofit consortium known as *interRAI* (*RAI* = Resident Assessment Instrument) to promote the use of assessment instruments and of cross-national comparisons as a foundation for improving care. *InterRAI*'s membership currently consists of 45 persons in 22 countries or regions: Australia, Canada, Czech Republic, Finland, France, Denmark, Germany, Hong Kong, Iceland, Israel, Italy, Japan, the Netherlands, New Zealand, Norway, South Korea, Spain, Sweden, Switzerland, Taiwan, the United Kingdom, and the United States.

Each of the cases unfolds within the cultural, social, and political realities of a particular country and regions within it. Because of the uneven deployment of these systems across most of the countries involved, the cases do not seek to compare data. Moreover, full implementation of the range of available instruments across long-term care domains has yet to be realized in any of the countries. The United States, which first implemented the *RAI*, is presented first, to provide background and context. The other studies proceed alphabetically by country: Canada, Iceland, Israel, Italy, Japan, Spain, and the United Kingdom.

**THE DEVELOPMENT OF THE RESIDENT ASSESSMENT INSTRUMENT**

The executive branch of the U.S. federal government commissioned the development of the first of what eventually became the *RAI* "family" of instruments in 1987, in response to mandates in the federal Omnibus Budget Reconciliation Act. These instruments are now routinely used in long-term care settings and, despite some ongoing criticism of them, have received the endorsement of the major long-term care provider trade organizations, the American Association of Homes and Services for the Aging (nonprofit organizations) and the American Health Care Association (investor-owned organizations).

Since 1992, *interRAI* has developed and tested other instruments in this "family," in some cases with partial funding through government contracts or from foundations in the United States and other countries. *InterRAI* licenses its assessment instruments, without charge, to any governmental or caregiver organization, because its members are committed to encouraging and assisting all stakeholders to use the instruments across a range of settings and services.

Each *RAI* instrument serves varied purposes for particular clients, providers, payers, and regulators. The most important of these are:

- Assessing and determining eligibility for services
- Contributing to care planning and management by clinicians
- Establishing a structure for allocating resources within an agency or organization
- Providing a basis for provider reimbursement
- Developing a sound basis for quality indicators

- Assisting in determining who uses which services
- Contributing to an understanding of which services and settings are appropriate for persons with various conditions
- Tracking frailty in individuals and specific populations over time
- Rationalizing services and systems
- Contributing to the projection of need and attendant costs

The RAI has had extensive development and testing for validity and reliability, including review by hundreds of geriatricians, nurses, clinicians, and other practitioners. The authors of the instruments provide definitions and training materials. Many commercial vendors supply computer software that supports the RAI. Because the Minimum Data Set (MDS) is used in every nursing home in the United States, there is considerable experience with the use of aggregate data for various purposes. A research archive at the University of Michigan contains more than 12 million assessments from 13 states, with multiple, longitudinal assessments on millions of residents. The national mandate in the United States has produced a federal database that is substantially larger and rapidly growing; these databases are increasingly in demand.

InterRAI has also devised parallel assessment systems for home care (RAI-HC), post-acute care (RAI-PAC), palliative care (RAI-PC), assisted living (RAI-AL), acute care (RAI-AC), and mental health (RAI-MH for psychiatric inpatient care). InterRAI works to balance the goals of making these systems specific to their applications yet compatible, so that individuals can be compared across types of care.

#### **WHY THESE EFFORTS MATTER**

The dramatic growth of the population of the very old, with the concomitant increase in the number of frail people, poses challenges to individuals, their loved ones, those who care for them, and policymakers. These challenges can be met adequately only if good information is available to those who must make decisions at the personal, clinical, managerial, and public policy levels.

A standardized assessment tool is a foundation for addressing a range of needs. Clinicians need information that will help them care for patients more effectively. Managers need information to most efficiently use the resources available to them for managing existing services and developing new ones. Frail persons and members of their families want assurance that services are being provided honestly and in a safe, preferably homelike, environment. Policymakers have responsibility for allocating scarce resources and ensuring public health.

A common assessment tool is also a useful first step in sorting out differences among and within countries. The characteristics of the frail are similar from country to country and from jurisdiction to jurisdiction. But there is considerable variation in how countries define needs and organize services. Even within the same jurisdiction there are often divergent understandings of who is being served, where, and why.



## THE RESIDENT ASSESSMENT INSTRUMENT (RAI)

InterRAI's instruments derive from the Resident Assessment Instrument (RAI) for nursing homes. (In the case study texts, the assessment systems for other modalities of care are differentiated with suffixes, such as the RAI for Home Care [RAI-HC].) The RAI system consists of two parts, the Minimum Data Set (MDS) and the Resident Assessment Protocols (RAPs).

1. *The Minimum Data Set (MDS)* contains the core assessment items necessary for a comprehensive assessment of a nursing home resident. The MDS includes individual assessment items and specifies definitions, time frames, and exclusions for the items as well as the response codes needed to ensure accurate assessment. It covers a wide range of functional domains, such as the resident's status in terms of cognition, communication, activities of daily living (ADLs), continence, psychosocial well-being, disease diagnoses, and health conditions.
2. *The Resident Assessment Protocols (RAPs)* are guidelines for additional, more sharply focused assessment and care planning. The MDS triggers use of the RAPs by identifying residents who need more specific assessment. The specific "triggers" are an individual resident's MDS-item responses that suggest the presence of a problem condition (e.g., mood, incontinence), a risk factor for decline (e.g., dizziness, wandering, use of trunk restraints or certain types of drugs, all of which elevate the likelihood of a fall), or the potential for improved function (e.g., the resident believes he/she is capable of increased independence in function or has a hearing problem that, if helped, could improve communication). Each of the 18 nursing home RAPs is a structured framework for developing plans that address the targeted problem by identifying treatable causes of the problem or risk factor or by effecting management interventions. The intent of the protocols is educational rather than prescriptive. Each protocol helps organize information from MDS items that can be used to inform the care planning process, that identifies additional information that may be needed, and that provides a context in which information about residents and their strengths, preferences, and needs is linked to the care plan options. Slightly different terms are used for the care planning protocols in the other RAI instruments: for example, there are Client Assessment Protocols (CAPs) for the home care instrument and Mental Health Assessment Protocols (MHAPs) for the RAI-MH.

## LESSONS FROM THESE CASE STUDIES

These cases offer evidence about (1) the RAI's effect on patient care, (2) its importance as a policymaking tool, (3) success in RAI implementation, and (4) obstacles to the instruments' adoption.

### **Patient Care**

- The RAI can contribute to improved direct patient care. It provides a means for an accurate, comprehensive understanding of the person in need of care; points to areas requiring special attention; and contributes to an ongoing care management plan.
- The RAI can be a powerful means to encourage coordinated, interdisciplinary activity on behalf of the resident.

### **Policymaking**

- The RAI can be an important tool in assessing the intensity of need and in planning the efficient use of resources to meet needs at both the provider and societal levels.
- The RAI can contribute to reimbursement policies that correspond to needs of the residents in a given program and, at the same time, offer incentives to care for those in greatest need.
- The RAI can contribute to developing quality indicators.
- Because preliminary, but substantial, data analysis confirms the perception that people with the same needs may be found in different settings and programs, the RAI can help in assessing whether resources are being used appropriately.

### **Successful Implementation of the RAI**

- The clinicians who are the primary, hands-on users of the RAI must be convinced that its use contributes to good care and is worth the opportunity costs involved.
- Education and training are essential components in developing clinician acceptance of the RAI.
- Program managers must see the utility of the consistent, accurate use of the instrument. Strong incentives for them to use the RAI instruments include the possibility of having more sophisticated systems for paying providers and for comparing quality across care programs.

### **Obstacles to Implementing the RAI**

- The RAI can be seen by persons in various professions as unnecessarily burdensome, less precise than existing instruments, too medically oriented, and an encroachment on the responsibilities of particular professions.
- It is difficult to introduce compatible, consistent assessment instruments across different systems and domains, each of which has a culture, history, and current approach to gathering and using information.
- The RAI can be the basis for reimbursement based on nursing home residents' levels of acuity and thus disrupt the status quo in reimbursement.

- The introduction, maintenance, and full exploitation of a data system can only develop over time and with a significant expenditure of resources.
- Staff turnover impedes the consistent, continuing use of the instrument.
- The use of the RAI is affected by such contingent factors as perceived crises that claim public attention.
- The RAI can assist but not determine the judgment of policymakers.

#### **RECOMMENDATIONS FOR THE FUTURE**

Each of these case studies carries an implicit sense of urgency about the need to collect good data in essentially compatible formats; to introduce systems of collection across service domains, regions, and nations; to make these data appropriately accessible to clinicians, providers, policymakers, and researchers in manners that are relevant and usable and that maintain confidentiality; and to increase and sustain the public investments that will ensure that appropriate data systems are maintained and adapted to the particular needs of clinicians, provider organizations, and regulators.

## **EXECUTIVE SUMMARY**

The Resident Assessment Instrument (RAI) is a uniform assessment system used to assess and plan the care of residents in virtually all U.S. nursing homes. It became a federally mandated system as part of a comprehensive set of nursing home reforms passed by the U.S. Congress in the Omnibus Budget Reconciliation Act of 1987 (OBRA '87).

The creation of Medicare and Medicaid in the mid-1960s provided the first significant influx of federal funds as payment for nursing home care in the United States. Federal regulations accompanied these funds. This watershed policy event was followed by rapid growth in the supply of nursing home beds and by the transformation of the U.S. nursing home industry. What had been a sector dominated by almshouses, county nursing homes for the poor, church-related nonprofit facilities, and small, individually owned proprietary homes rapidly became a predominantly for-profit industry dominated by multistate firms (nursing home “chains”). In addition, the first 20 years of Medicare and Medicaid were plagued by scandals about seriously substandard care in nursing homes, conditions attributed to a largely ineffective regulatory system.

The nursing home provisions of OBRA '87 resulted from these concerns about quality and constituted the most comprehensive set of federal reforms addressing the regulation of nursing homes since the passage of Medicare and Medicaid. While OBRA '87 mandated many changes, the RAI was one of the most fundamental. Beyond its use in resident assessment and individualized care planning, the RAI provides resident-level data used to determine Medicare eligibility, to generate quality indicators used in the inspection of nursing homes by government agencies, to plan quality improvement activities by facilities, and to adjust nursing home payment rates to reflect differences in the amount and type of care residents need.

Since the implementation of the RAI and most other OBRA '87 regulations in 1990, researchers have found significant improvements in both process and outcome quality measures. Further, a number of other countries have indicated interest in using the RAI for assessment or reimbursement purposes. Despite these developments, the RAI and the rest of the federal regulations mandated by OBRA '87 came perilously close to being eliminated during the mid-1990s and remain somewhat vulnerable to the vagaries of state and national politics. This paper examines the factors that led to the adoption of the RAI and the other OBRA '87 nursing home reforms; it explores the factors that make quality improvements through federal regulation essential but politically vulnerable; and it summarizes the lessons to be learned from the process of developing and implementing the RAI.

The enactment of the OBRA '87 nursing home reforms and the mandate to use the RAI faced considerable barriers in the United States—barriers that differed significantly from those faced in other countries. First, the U.S. nursing home industry is largely private and proprietary, and much of the industry views regulation as interference with business, even when the goal is quality improvement. Second, many lawmakers share this view, and disputes over the appropriate role of the federal government, particularly in the regulation of industry, are highly politicized. Finally, in political

conflicts, the nursing home industry has traditionally had a significant advantage over residents, family members, and consumer advocacy groups, and the industry has been a more consistent and effective advocate for its positions than have groups representing these other constituencies.

Despite the traditional barriers to regulatory reform, several factors combined to make the OBRA '87 reforms possible. First, an attempt by President Ronald Reagan to reduce nursing home regulation at the federal level was met with strong opposition from consumer advocacy groups and congressional opponents of the president. The result was a commissioned study by the National Academy of Sciences' Institute of Medicine (IOM). The IOM's research activities—and the organization's prestige—lent scientific credibility to its recommendations. Moreover, the IOM recommendations provided a core around which supporters of quality improvement could coalesce.

A second factor facilitating the adoption of the reforms was the formation of the national Coalition for Quality Care. This coalition included consumer advocacy groups, associations of health care professionals, and nursing home providers. It reached consensus on most IOM recommendations and supported them before Congress. As a result, Congress, with strong bipartisan support, adopted nearly all of the IOM recommendations, including the requirement for a uniform, comprehensive functional resident assessment.

The Centers for Medicare & Medicaid Services (CMS, formerly the Health Care Financing Administration) and the research team that developed the RAI also made a number of important decisions that facilitated the RAI's implementation. To maintain support from the Coalition for Quality Care, the team involved all key stakeholders in the process of RAI development. Consumer advocates, providers, and health care professionals all bought into the system, deflecting initial industry attempts to limit the scope of the RAI. In addition, CMS and the development team were committed to making the RAI clinically relevant, feasible for providers, and politically defensible.

Although several researchers found significant improvements in both process and outcome quality measures as a result of the implementation of the RAI and the other OBRA '87 nursing home reforms, the OBRA '87 reforms were nearly repealed in 1995 as part of a larger attempt to change the nature of the Medicaid program, which pays for the care of about two-thirds of all nursing home residents. At that point, part of the nursing home industry supported repeal of the OBRA reforms, particularly the enforcement provisions. But consumer advocates, aided by researchers, were able to use the empirical evidence about the positive effects of the RAI and other OBRA provisions to effectively oppose the dilution of federal regulations. Once consumer advocates redefined the issue as one of quality of care, opposition to the repeal spread from congressional Democrats to moderate Senate Republicans, and the OBRA '87 reforms were saved.

The passage of the OBRA '87 nursing home reforms and the subsequent implementation of the RAI, as well as their near-repeal, reveal important lessons about attempts to improve quality in American nursing homes. It is clear that because of the highly politicized nature of regulation in American politics, all regulations remain politically vulnerable, even those aimed at improving quality and even when originally enacted with strong support from both consumers and providers. But it is

equally clear that consumer advocates can use research findings to identify practices and policies that promote quality and can redefine political conflict over regulation to focus on patients and their quality of care. Regulations embodying policies that both consumer advocates and providers view as clinically relevant and useful are more sustainable over time.

## **INTRODUCTION**

Since the passage of Medicare and Medicaid<sup>1</sup> in the mid-1960s, nursing home policy in the United States has largely been a product of two factors. First, nursing homes and their residents have been and continue to be affected by policies aimed at the acute care sector, particularly those policies intended to reduce hospital use and costs. These have had significant spillover effects on nursing home policy and operations, including financing, utilization, and resident case mix. In addition, nursing home policy has been episodically affected by scandals about poor care in nursing homes (Hawes 1987; Vladeck 1980). Indeed, for decades, major reform efforts have often been tied either to a series of tragic events involving multiple deaths<sup>2</sup> or to public reports of seriously substandard care that have captured the public's attention and, at least temporarily, generated the necessary political support for new legislation or regulation (California 1983; New York 1975, 1976; Ohio 1978, 1979).<sup>3</sup> Occasionally, however, scientific endeavors have fundamentally affected nursing home policy. These endeavors have, at times, influenced both the process of policy development and debates about whether to retain or alter key federal regulatory policies. This paper recounts one of these episodes.

The development, implementation, and retention of the nursing home reforms contained in the Omnibus Budget Reconciliation Act of 1987 represent key examples of the effect of science and politics on policy. The purpose of this case study is to illustrate the interplay of science and politics by focusing on one particular aspect of the OBRA '87 nursing home reforms: the federally mandated Nursing Home Resident Assessment Instrument. The paper also seeks to illuminate the politics of long-term care and the conditions under which resident-centered reforms can be enacted, implemented, and sustained, as well as the way in which research findings may be used to structure policy and policy debates. In addition, this case study illustrates important differences between nursing home reform in the United States and other countries.

## **BACKGROUND: THE POLITICS OF LONG-TERM CARE**

Before the mid-1960s, state licensure laws governed nursing homes. Federal funding was quite limited, and federal standards were mainly tied to the use of federal funds (e.g., Federal Housing Authority) to finance construction of facilities. Two dynamics, however, generated greater federal involvement in nursing home regulation. First, a series of federal reports were highly critical of the shoddy conditions and abysmal quality of care in nursing homes (U.S. DHEW 1958; U.S. Senate 1956, 1957, 1960a, 1960b). Second, the introduction of federal payment for nursing homes with Medicare

and Medicaid funds generated a demand for greater federal oversight to ensure adequate accountability for and control over these large public expenditures (IOM 1986; Vladeck 1980). Federal standards were initially limited to extended care facilities (ECFs) intended only to provide skilled nursing or rehabilitative care and to facilitate shorter hospital stays for Medicare beneficiaries. Within a few years, however, federal standards were extended under the Medicaid program to cover intermediate care facilities that provided long-term “custodial” care.

Medicare and Medicaid, which fostered the emergence of and serve as the financial foundation for the current nursing home industry, also fostered the development of the politics of long-term care. There is often a clear nexus between politics and the content of policy (Lowi 1964; Schattschneider 1960). Indeed, in some cases, policy creates programs that essentially generate their own “politics.” Certainly this has been true with respect to nursing home care. Public payments essentially created an industry that, if it has not dominated the subsequent policy process, has had the most sustained effect on policy over time. These new sources of funding for nursing home care and their cost-based reimbursement policies attracted Wall Street investors and real estate developers to a sector that had previously been populated by not-for-profit, church-related, and fraternal organizations; county poor farms; and small individually owned, “mom and pop” proprietary homes. The diverse and locally controlled pre-1960s nursing home sector metamorphosed into a largely for-profit industry dominated by “the chains” (multifacility systems that own and operate nursing homes in several states and whose stock is publicly traded) with increasing concentration of ownership nationwide in relatively few corporate entities.<sup>4</sup>

Each industry has its own economic interests, and the nursing home industry is no exception. To protect its interests, the industry has become a major contributor to political campaigns at both the state and national levels (Pear 1997; Vladeck 1980). One of the chief lobbyists for the proprietary nursing home industry—himself a nursing home owner—chaired the Democratic Party’s Business Council, a group of donors who each contributed \$10,000 or more per year to the party during the Clinton administration, and he became the party’s finance chairman. At the same time, nursing home interests contributed more than \$1.1 million to Bill Clinton’s 1996 presidential campaign (Weisskopf 1997).

If government policy has essentially created a provider industry and the conditions under which that industry has flourished and attained political power, it has done little to support similar access to influence by consumers. Nursing home residents are often naturally disadvantaged by the very disabilities that cause them to need nursing home care. Moreover, long-term custodial care is the province of Medicaid. Thus, elderly people who need long-term custodial care, such as those with Alzheimer’s disease, must exhaust their incomes and assets, paying for needed care out of their own pockets, before becoming eligible for public assistance. For many frail elderly in the United States, public policy has essentially added poverty to the burden of the multiple chronic diseases that force them into nursing homes.

The imbalance in resources between consumers and providers of long-term care has always been striking. Medicare and Medicaid payment policies accept as allowable costs the nursing homes’ dues to

organizations that represent industry interests before Congress, state legislatures, and administrative agencies, but no similar, sustained public funding has been available for groups representing residents. Resident advocacy groups whose sole focus is long-term care policy, such as the National Citizens Coalition for Nursing Home Reform (NCCNHR), are usually shoestring operations. Unlike provider trade associations, such as the American Health Care Association (AHCA), consumer advocacy groups do not have political action committees to lobby for them. Similarly, the long-term care ombudsman program, which is often thought of as an advocacy group for residents, is barred from lobbying, and limited funding has constrained its efforts to educate policymakers about consumer needs and interests (IOM 1995). Well-organized and well-financed consumer advocacy groups that focus only on nursing homes or long-term care are a rarity. As a result of their structural and fiscal limitations, groups representing consumers of nursing home care, such as the NCCNHR, rely on the media to focus occasional attention on quality problems and depend on the good will and skills of the small number of policymakers who champion nursing home reform issues.

Some consumer advocacy groups whose focus is more general and whose resources are much more substantial than the NCCNHR's, such as AARP (formerly the American Association of Retired Persons) and the Alzheimer's Association, do support nursing home reform. But because these organizations represent constituents who have many other pressing interests that must be addressed in the policy arena—including Social Security, basic biomedical research, and Medicare policy in general—they rarely put nursing home issues at the front of their primary policy agenda.

This environment, with its strong industry sector and its weak consumer and advocate sector, is not unique to the politics of long-term care. Nonetheless, it was this environment that ensured that during the first 20 years of Medicare and Medicaid's involvement in long-term care, policy changes were mostly incremental, and legislation tended to focus on nursing home reimbursement issues. The industry tended to dominate legislation addressing reimbursement and was the most consistent and effective influence over the development and implementation of other aspects of regulation (Hawes 1987; Vladeck 1980). The result was a regulatory process that all too often failed to protect residents or ensure quality.

Between the passage of Medicare and Medicaid and the enactment of OBRA '87, a series of state reports documented abysmally poor care and failed regulatory processes (Arkansas 1978; California 1983; Colorado 1978; Connecticut 1976, 1980; Florida 1981; Illinois 1984; Maryland 1973; Minnesota 1976; New Jersey 1978; New York 1975, 1976; Ohio 1978, 1979; Texas 1978; Virginia 1979). Reports by the federal agencies regulating nursing homes (U.S. DHEW 1971, 1975) and by congressional agencies and committees (U.S. GAO 1971; U.S. House of Representatives 1985; U.S. Senate 1970, 1971, 1974–75) essentially echoed the same findings and criticisms. These reports found unsafe and unsanitary conditions, including failure to meet state fire codes and federal life safety codes; abuse; neglect; malnutrition; overuse of physical and chemical restraints; medication errors; and failure to provide prescribed medical treatments and therapies. Moreover, the studies determined that such substandard conditions were widespread.



The state and federal reports almost universally cited the same factors as causing or contributing to substandard care.<sup>5</sup> Most of the studies made the following arguments:

- Despite the existence of federal standards, there was considerable variation in quality across facilities and substantial differences in the performance of state regulatory systems.
- Federal and state standards were inadequate to protect the health, safety, and rights of residents.
- The inspection process focused on paper compliance with standards and failed to capture the realities of the day-to-day life of residents.
- Federal regulations did not provide states or the federal government with an adequate range of compliance mechanisms.
- When states adopted a range of sanctions, most failed to make effective use of the available remedies.
- State and federal regulatory systems allowed nursing homes with a history of seriously substandard care to remain in operation year after year.

The genesis of these failures in regulatory policy was not wholly mysterious. Many observers attributed it, in whole or part, to the power of the nursing home industry (Mendelson 1974; Moss and Halamandaris 1977; Townsend 1971; U.S. Senate 1974–75; Vladeck 1980). Despite reports about widespread problems and systemic regulatory failures, however, comprehensive reform did not occur. Those reforms that did occur were, for the most part, extraordinarily limited. For example, despite reports of widespread and serious quality problems, the only major new federal rule imposed during the first 15 years of Medicare and Medicaid was the federal life safety code. First applied solely to skilled nursing facilities, it was later applied to all certified facilities as reports of unsafe conditions and multiple fire deaths persisted.

Similarly, the U.S. Senate Special Committee on Aging (1974–75) published a series of shocking reports entitled *Nursing Home Care in the United States: Failure in Public Policy*. The only piece of federal legislation enacted in the wake of these revelations created the federal Office of Inspector General (OIG) in the U.S. Department of Health and Human Services and mandated development of Medicaid Fraud Units in the offices of the state attorneys general to prosecute cases of provider fraud. More far-reaching efforts, such as implementation of the Patient Appraisal and Care Evaluation to assess residents and develop an outcome-oriented survey system, as well as subsequent reforms proposed during the Carter administration, fell into limbo in the face of opposition from the nursing home industry (IOM 1986).

Even in states that issued highly critical reports, reforms were seldom far-reaching. For example, an Ohio legislative study commission's reports provided a troublesome, and all too familiar, picture of conditions in many nursing facilities and offered a comprehensive analysis of the regulatory failures that allowed such conditions to persist (Ohio 1978, 1979). As a result, legislators introduced two bills incorporating the study's recommendations. One bill, which addressed reimbursement and discrimination against Medicaid recipients, was enacted, but the other, an omnibus quality improvement bill addressing standards of care, the survey process, and enforcement remedies,

failed. It was not successfully revived until a decade later, following the passage of the OBRA '87 nursing home reforms.

Nationally, the nursing home industry was able to limit reform efforts in two basic ways. First, it was often able to appeal to legislators who had an antipathy to government regulation by defining the issue as one of overly burdensome regulation and arguing that nursing homes were “the most regulated industry” in the country. Second, the industry often defeated reform by arguing that proposed regulations would impose substantial additional costs. For example, the Carter administration argued that its proposed regulations would cost about \$80 million a year. Industry-hired consultants estimated the cost at \$586 million for the first year of implementation and \$435 million annually thereafter (Applied Management Sciences 1980).<sup>6</sup> As a result of the dispute and the industry’s power, the proposed Carter reforms went nowhere until the final hours of the administration, when one part of the proposed reforms, a provision making adherence to a set of residents’ rights a condition all nursing homes had to meet in order to participate in Medicare or Medicaid, was published as a new regulation (IOM 1986, 247). Even that rule was immediately rescinded by the incoming Reagan administration as part of its “regulatory reform” initiative.

All these attempts at nursing home reform were played out in the context of an ongoing debate—one that lies at the heart of much political conflict in the United States. The nursing home industry in the United States is predominantly proprietary. As a result, the industry tends to view regulation as government interference in the operation of its “business.” The more refined version of this argument is that the industry, left to itself and the forces of competition in the marketplace, could provide a better “product” than a nursing home industry constrained by the fetters of governmental regulation. Such regulation, this argument contends, perverts the market, stripping it of its purported ability to generate better products at lower costs. Any attempt at new regulation, even regulation aimed at improving residents’ quality of care and quality of life, was immediately embroiled in this debate.

Issues involving the allocation of public resources are inherently political. Even in countries where long-term care and nursing home services are provided by local or national agencies, questions regarding who has the authority to allocate resources and who should receive them cause political conflict. Outside the United States, however, these conflicts rarely inspire such ideological fervor. This country is unusual in the array of powerful, well-funded political interests that become involved and in the tendency, during eras of deregulation, for enormous quantities of money to move from the public coffers into the private sector.

#### **DESIGN: GENESIS OF THE RAI AND OBRA '87 REFORMS**

The passage of the OBRA '87 nursing home reforms seemed to herald a new era of politics and policymaking in long-term care. Several factors contributed to the enactment of what were arguably the most sweeping set of reforms to the federal regulation of nursing homes since the passage of Medicare and Medicaid.

The OBRA '87 reforms were based on the recommendations of a panel established by the prestigious National Academy of Sciences' Institute of Medicine (IOM). Democratic congressional reaction to the Reagan administration's proposal to reduce nursing home regulation was swift and negative. In an agreement worked out between Congress and the administration, the IOM was charged with evaluating the regulatory process and making recommendations on how to improve quality of care and quality of life for the nation's nursing home residents.

The commission conducted a two-year study that included public hearings, a review of state reports completed during the preceding decade, commissioned papers on specific aspects of nursing home quality assurance, and other attempts to understand the existing systems of federal and state regulation and how they could be improved. In 1986, the IOM committee issued its report, *Improving the Quality of Care in Nursing Homes*, which contained a wide array of recommendations aimed at improving the standards governing nursing homes participating in Medicare and Medicaid, refocusing and enhancing the survey process for monitoring the performance of facilities, and expanding the availability and use of a range of enforcement remedies (IOM 1986).

With strong bipartisan support, Congress adopted nearly all of the IOM committee's recommendations. The broad support enjoyed by the legislation resulted from a number of factors. First, the IOM used research findings, whenever possible, to craft and support its policy recommendations. Some recommendations, such as reductions in the use of physical restraints and reliance on the principles of geriatric assessment, were based on empirical evidence about good clinical practice, with high-quality, innovative nursing homes in the United States and other countries serving as a model of what was possible. Similarly, the IOM carefully studied the best state regulatory models, drawing on their example of what could be achieved.

Second, the 1986 IOM report clearly documented severe and widespread quality problems and significant deficits in existing regulatory policies and practices. This placed the issue squarely on the public agenda, giving impetus to the formation of a coalition of consumer advocacy groups, unions, health care professionals, and nursing home industry representatives.

Third, this diverse coalition, called the Campaign for Quality Care and organized by the NCCNHR, had a major impact on the legislative process. The coalition met weekly during the period following the release of the IOM report to develop a list of priority areas for legislation. The coalition's members ultimately reached consensus on recommendations and presented these recommendations, as a group, to Congress (Edelman 1997–98). The formation and action of this fragile coalition—the first to meet at the national level and to vote and reach consensus on key issues to take before Congress—was a major factor contributing to the passage of the OBRA '87 reforms.

OBRA '87, rooted deeply in the IOM committee's recommendations, represented a comprehensive and innovative approach to regulation. First, it mandated simultaneous changes in three fundamental components of the federal regulatory system: (1) the standards, (2) the process for surveying or inspecting homes and determining whether facilities were in compliance with the standards, and (3) the enforcement system for dealing with those facilities that failed to comply with the standards.

All three components were to be resident-focused and outcome-oriented. For example, the new standards spoke to the process of care that was expected and to the requirement that care would promote “the maximum practicable functioning” for each individual resident. Further, OBRA '87 gave residents' rights and quality of life the same degree of regulatory importance as the provision of high-quality care. The new inspection procedures also focused on process and outcome quality. They incorporated interviews with residents, families, and ombudsmen about residents' daily experiences in the homes as well as direct observation of residents and the care they were receiving. Finally, the new enforcement system focused on outcomes, mandating that states adopt a wider array of sanctions to be used when unacceptable outcomes were identified. Their use was to be tailored to the nature and severity of the deficiencies found during surveys or complaint investigations.

### **The Problem: What Led to the RAI?**

One of the central IOM recommendations was that the Centers for Medicare & Medicaid Services (CMS)<sup>7</sup> should mandate use of a uniform nursing home resident assessment instrument, initially propounded by IOM member and committee chair Sidney Katz, M.D. This recommendation emerged from several concerns. Several prior studies that had identified significant and widespread quality of care problems had attributed them to nursing facilities' failure to adequately identify and treat residents' problems and care needs. Assessment information was often inaccurate, incomplete, and unrelated to the care plan (Hawes et al. 1995; Morris et al. 1990). For example, nursing homes typically underdiagnosed and undertreated residents' mood problems and delirium (Liston 1982; Rovner, German, and Brant 1991). Similarly, overuse of physical restraints and inappropriate use of psychotropic medications were widespread (Evans and Strumpf 1989; Harrington, Tompkins, and Curtis 1992; Kane et al. 1993; Ray, Federspiel, and Schaffner 1980). Other poor care practices were also common, including overuse of urinary catheters; deficient treatment of incontinence; inadequate prevention and resolution of pressure ulcers; inattention to nutritional problems; a lack of regard for hearing, vision, and dental problems; and inadequate psychosocial interventions, including a lack of effective behavior management programs (Gugel 1989; Himmelstein, Jones, and Woolhandler 1983; Howard, Strong, and Strong 1977; Marron, Fillit, and Peskowitz 1983; Michoki and Lamy 1976; Ouslander and Fowler 1985; Ouslander and Kane 1984; Ouslander, Kane, and Abrass 1982; Schnelle et al. 1988; Starer and Libow 1985).

The need for uniform and comprehensive assessment in long-term care was well recognized (Kane and Kane 1981; Katz 1983), and it was clear that one mechanism for solving these problems would be to improve assessment and care planning for residents. An assessment of each resident's strengths, needs, and preferences constitutes the foundation for developing an appropriate individualized plan of care. Moreover, the positive effects of comprehensive geriatric assessment on the health and well-being of older persons had been demonstrated in several studies (Applegate et al. 1983; Hendricksen, Lund, and Stromgard 1984; Rubenstein, Rhee, and Kane 1982; Tulloch and Moore 1979).

Finally, prior studies had suggested that the standards governing nursing homes were too focused on structural aspects of quality. As a result, the survey process had usually focused on the “capacity” of the facility to meet those structural standards rather than on the quality of care and quality of life experienced by residents on a daily basis (IOM 1986; New York 1976; Ohio 1979; U.S. DHEW 1975, 1976). The IOM therefore wanted a uniform assessment instrument that could provide data about the resident at admission and periodically thereafter.

The IOM recommendation on uniform assessment was intended to achieve the following objectives, at a minimum:

- To improve clinical practice in nursing homes, ensuring that all residents would have a comprehensive assessment that would inform the development of each resident’s individualized plan of care
- To refocus the regulatory process on individual residents—the quality of their daily lives and well-being over time—rather than on facilities and facility capacity
- To develop quality indicators (from data about the residents gathered at admission and periodically thereafter) that could be used to generate resident-centered measures of process and outcome quality

### **The Opportunity**

The conditions that led to the passage of OBRA ’87 represented an opportunity for the development and implementation of the uniform resident assessment system supported by the IOM. As Weissert and Weissert (1996, 237) observe, “Nonincremental change sometimes occurs first with an incremental step that provides knowledge to policymakers and mobilizes public or group support. In a second stage, convergence toward comprehensive reform occurs.” In the case of the OBRA ’87 reforms, the “incremental step” was the IOM committee and the conditions that led to its existence. The committee, in carrying out its charge, did the very things Kingdon (1984) described as part of the “softening up” process that is essential to comprehensive reform. It held public hearings; members gave speeches; and the chair of the committee, along with two or three other members, met with congressional staff to brief them on what the committee was finding and to set the stage for legislative enactment of the committee’s recommendations.

As noted earlier, the IOM committee’s activities heightened the visibility of nursing home quality issues at the federal level, helped move nursing home issues onto the public agenda, and provided a comprehensive set of recommendations around which groups could coalesce. In addition, the IOM committee lent its expertise to defining and solving the problem, giving the task an aura of “science” and relieving congressional committees of the time-consuming and highly technical task of developing legislative proposals from scratch. Finally, the OBRA ’87 reforms were the culmination of more than a decade of criticisms and calls for reform—what Kingdon (1984) called the “overwhelming power of an idea whose time has come.”

The remarkably broad-based support for the OBRA '87 reforms represented a singular opportunity for comprehensive reform rather than the incremental efforts that had preceded OBRA. Not since the passage of Medicare and Medicaid had there been such a high level of agreement on nursing home reform issues among consumers and providers. Not only would Congress pass the legislation, but there was a good chance that the letter and spirit of the law, including the resident assessment provision, would be fully implemented.

Thus, in OBRA '87, Congress required that nursing facilities conduct a “comprehensive, accurate, standardized, reproducible assessment of each resident’s functional capacities.” Congress referred to this as the Minimum Data Set (MDS) and specified the basic functional areas that had to be included in the MDS. CMS was charged with developing the instrument and regulations for implementing this requirement. This assessment became known as the Nursing Home Resident Assessment Instrument, or RAI, and incorporated the MDS.

### **The Constraints**

The fundamental constraint facing policymakers and the research team charged with developing the RAI was the high likelihood that the consensus among providers and consumers would end. It is common for an industry that will be subject to a regulatory system to attempt to exert its influence on the agency charged with implementation (Thompson 1983; Wilson 1989). A breakup of the Coalition for Quality Care would have set the stage for the nursing home industry to weaken or delay the regulations implementing OBRA '87. Indeed, this has been a common pattern in other areas of health policy: recognizing that they are trapped in the converging streams of problem definition, policy solutions, and a changing political climate, interest groups often abandon the legislative battle and instead attempt to delay a new law’s implementation or to chip away at the regulations promulgated to implement it (Weisskopf 1991).

Bureaucracies often play a significant role in formulating policy, but perhaps their most significant role is in implementing policy and administering programs over time (Morone 1993). Moreover, the “real,” or operational, policy is the policy that is actually implemented rather than the policy enacted by the legislative body. In health care policy as in other areas, the bureaucracy charged with developing regulations and implementing legislation often modifies the final impact of a policy in order to address competing interests or goals, to respond to special interest groups, or to make a program work (Altman and Sapolsky 1976; Wilson 1989).

Certainly, CMS staff had ample evidence to support the notion that if they went “too far” in the regulations they developed to implement the OBRA provisions, they would arouse the ire of the industry. For example, in 1978 Congress had mandated uniform hospital reporting for those institutions participating in Medicare and Medicaid programs. In the view of associations representing the hospital industry, the agency overstepped its bounds in drafting the regulations and developing the manual that specified the contents and processes of the uniform reporting system. The hospitals

complained to Congress, and the House of Representatives voted to eliminate the funds the agency needed to implement the program. Eventually, a compromise was reached, one that reduced the amount of data to be collected to a level the hospitals deemed was not too intrusive (Thompson 1983). Like all bureaucracies, CMS had to walk a delicate balance in implementing the OBRA '87 reforms while attempting to avoid alienating powerful external interest groups (Meier 1985; Wilson 1989). This was particularly true with respect to development and implementation of the RAI.

This dual possibility—that the Coalition for Quality Care would dissolve and that CMS might engender industry opposition—was particularly troubling, because earlier attempts to implement a uniform resident assessment had failed. During the mid-1970s, the Office of Nursing Home Affairs, then part of what is now the Department of Health and Human Services, sponsored development of a Patient Appraisal and Care Evaluation. This form was to be used for resident assessment, but the goal was that the resulting resident-level data would eventually be used in a more outcome-oriented survey process and as the basis for reimbursement (Lynch 1976; U.S. DHEW 1976). The nursing home industry argued that the system was too burdensome and complex for implementation as a regulatory requirement. As a result, the agency abandoned the proposed regulation and instead published the instrument as a tool nursing homes could use voluntarily (IOM 1986). Similarly, the Carter administration proposal on uniform assessment, abandoned by the Reagan administration, was partly the victim of renewed industry opposition. As previously discussed, the substantial difference between the administration's estimate of the cost impact of the proposed regulation and the one put forward by the nursing home industry doomed the proposal (Applied Management Sciences 1980; IOM 1986; U.S. DHHS 1980).

Finally, cost was a constraint. OBRA '87 required that the federal government and the states recognize any increased provider costs associated with meeting the new standards and adjust Medicare and Medicaid rates accordingly. Growing concern about federal budget deficits and the rising cost of nursing home care meant that any added cost would be a significant consideration in evaluating the utility and feasibility of regulations implementing the OBRA '87 mandates.

#### **OUTREACH: CLINICAL AND TACTICAL DECISIONS IN DEVELOPING THE RAI**

CMS and the research team that developed the nursing home resident assessment system were well aware of the constraints and potential pitfalls they faced. It was clear from the outset that the development of the RAI would involve both scientific and political decisions and actions.

CMS came to the RAI<sup>®</sup> development process with a clear understanding of the constraints and potentially countervailing forces it faced. CMS staff recognized that the OBRA '87 reforms were so sweeping that CMS might increase OBRA's effectiveness by focusing special attention and effort on selected aspects of the legislation. As a result, CMS staff made a tactical decision to concentrate their initial efforts on some of OBRA '87's most basic provisions. These included implementing resident assessment, eliminating (or at least reducing) the use of physical restraints, reducing the inappropriate use of psychotropic medications, strengthening residents' rights and enhancing their

quality of life, and enhancing the training and testing of nurse's aides. CMS viewed these as achievable goals, strongly related to resident well-being and amenable to influence by CMS interventions such as training and the survey process.

CMS also worked closely with the independent research team that had been selected to develop the RAI. It was clear from the outset that the research team was charged with developing an assessment system that was clinically relevant, feasible for the existing industry, and defensible in terms of the burden it would impose on providers. While the last two goals could be viewed as political, the project team also viewed them as valid from a quality of care perspective. In the research team's view, the RAI would be a failure if the existing provider community could not reliably use the assessment system. Similarly, achieving clinical excellence would be meaningless if, in the process, the RAI were to generate so much political opposition from the nursing home sector that the regulations would be abandoned. At the same time, the research team and CMS felt strongly that the chief aim of the RAI system was to improve clinical practice in nursing homes across the country. To achieve these multiple goals, the project team made several decisions.

### **Content of the RAI**

One key decision concerned the RAI's scope. Initially, the research team focused on only one of the two basic substantive components of the RAI, the Minimum Data Set for Nursing Home Resident Assessment and Care Screening (MDS). The MDS is the core functional assessment instrument in the RAI and covers such congressionally mandated domains as physical functioning in the activities of daily living (ADLs), cognition, continence, mood, behavior, nutritional status, communication, vision, and psychosocial well-being. Development of this component was the project team's first task. The team also articulated the purpose of the MDS assessment, which was to identify a resident's strengths, preferences, and needs in key areas, providing a comprehensive picture of the resident's functional status in language that would be common across all disciplines. This assessment was intended to help the nursing facility staff develop a comprehensive and individualized plan of care for each resident.

The team had 18 months in which to develop, test, and revise the RAI before the deadline by which the secretary of the Department of Health and Human Services had to formally designate the instrument called for in OBRA '87. Twelve months into the project, CMS directed the research team to include additional assessment guidelines in the RAI. The team had been working on 18 problem-focused Resident Assessment Protocols (RAPs) in specific problem areas or conditions that were common among nursing home residents or that represented a severe health risk if unaddressed. The RAPs represented an attempt to summarize the best available information on the nature, prevalence, and causes of problems and conditions afflicting nursing home residents; by helping staff to recognize these problems and conditions, the RAPs could assist them in making key care-planning decisions. Each RAP included a set of MDS items known as *triggers*—specified responses to these MDS items that would indicate that the resident being assessed had a problem, a risk for decline, or the potential for improved function. If such



triggers were present, the RAP provided guidelines that specified additional, highly focused assessment to identify treatable causes of the condition and to focus decisions about care planning for the resident.

The research team initially intended to issue these RAPs, along with suggested care planning guidelines, as educational materials; their use by facilities would be voluntary rather than part of a regulatory mandate. One key CMS staff member, however, argued that the RAI's success would rest on its ability to inform the development of an individualized plan of care for each resident based on his or her needs, strengths, and preferences. This CMS policymaker envisioned the survey system as providing incentives for the actual provision of care and services specified in the care plan. The argument was convincing, and CMS moved to bring the mandated assessment system as close as possible to one in which there would be clear and specific guidelines regarding decisions about the content of the care plan. CMS asked the project team to include the RAPs along with the MDS in the resident assessment instrument. At the same time, this decision entailed stripping away the explicit material on what should be included in a care plan for each RAP area, since the congressional mandate on standardized assessment could not possibly be stretched to include explicit guidelines on the interventions that should be implemented in the care plan. Thus, the CMS bureaucracy's clinical and quality of care concerns dictated the expansion of the RAI to include the RAPs while its tactical concerns, driven by the desire to avoid generating provider ire, limited the content of the RAPs and explicit links to care plan specifications. The decision to include the specialized RAP assessment guidelines in the RAI significantly increased the clinical utility of the MDS. At the same time, the decision not to include the material that would have linked the assessment information to specific care plan interventions probably limited the system's eventual clinical impact.<sup>9</sup>

### **National Advisory Committee**

CMS specified that the RAI project would have a national advisory committee that would include representatives of consumers, providers, and regulators.<sup>10</sup> The initial goal was to ensure that all the key stakeholders, many of whom had participated in the Campaign for Quality Care, would be routinely informed about what was going on and would be consulted about key decisions. Research team members, particularly John Morris, the task leader for development of the RAI, felt that the advisory committee could be used even more creatively, and so its members were asked to volunteer as reviewers or to join substantive workgroups. The substantive workgroups were assigned the task of developing items, response categories, and definitions in 18 different areas, or domains, of the MDS (e.g., nutrition, activities, behavior, psychosocial well-being). They were also asked to work on the development of the second component of the RAI—that is, the 18 RAPs. The workgroups were comprised of project staff, members of an expert clinical panel, other consultants who were clinical experts, and volunteers from the advisory committee or the organizations they represented.

This use of the advisory committee had multiple advantages. It expanded the substantive expertise available to the research team, and it involved key stakeholders in critical decisions about the focus and content of the RAI. By involving them deeply in the development process, the project team virtually

ensured that the key stakeholders would come to view the clinical utility of the system as their main objective. This buy-in by nearly all the stakeholders, and certainly by those who actively participated in the workgroups, helped maintain unity of purpose and vision. This decision also increased, or at least maintained, political support for the RAI among many of the groups that had participated in the original Campaign for Quality Care, including the provider associations. Finally, the involvement of key stakeholders from groups representing consumer advocates, nursing homes, ancillary providers, and nursing home staff helped ensure the feasibility of the system that was developed.

## **Burden**

As has been noted, a major reason for the failure of CMS's earlier attempts to require comprehensive resident assessment was that the systems were viewed as too complex or unwieldy by the nursing home industry. In addition, the industry was able to portray the system proposed during the last years of the Carter administration as too costly. The RAI project team recognized the danger that its proposals could be cast in the same light, and it made three decisions designed to minimize this risk:

- First, the team concluded that it had to collect meaningful data from nursing homes on their existing assessment practices, including data on which staff members participated in assessment and care planning. Facilities were also asked to report the amount of time spent on assessment per resident. Similar data were collected from these facilities about their use of the RAI during reliability trials.
- Second, the research team decided that the additional “burden” the RAI placed on providers was acceptable. The data indicated that, on average, facilities would spend about 20 minutes more per resident on the MDS admission or annual assessment than they were currently spending. CMS and the project team concluded that this increase was defensible, especially since the difference was expected to drop slightly (by about five to ten minutes) as staff became more familiar with the RAI and as they began to maintain medical records in all disciplines in a way that was consistent with the RAI. CMS, the team, and the advisory committee reviewed the scope and content of the RAI and were unable to identify any major sections or domains that could be eliminated without compromising the clinical utility of the assessment process. They therefore concluded that an admission assessment that took an hour, on average, and an annual reassessment that typically took 45 minutes did not present an unreasonable burden and were probably defensible, since it added key domains (e.g., mood and behaviors) to the usual assessment and given the overwhelmingly positive response to the RAI by facility staff participating in field trials (see below).
- Third, the team recognized the importance of being able to defend the RAI against the argument that it increased paperwork and took time away from resident care. The team concluded that one way to address this potential criticism would be to document the benefits of the assessment. Thus the project team asked detailed questions of the facility staff who participated in the various

reliability and validity field trials, inviting them to identify items in the MDS that they felt were superfluous, MDS items that were not part of their standard assessment process, and any sources of information required by the MDS that they did not routinely use under current practices. The project team also asked participating facility staff whether they felt that the additional time associated with the RAI was worthwhile.

The results of this survey were striking and helped demonstrate the value of the additional effort. The facility nurses who tested the MDS reported that the MDS covered more domains or areas than the assessment instruments they were currently using. Those additional domains included such areas as mood, psychosocial well-being, oral status, and indicators of rehabilitation potential. Two-thirds of the facility nurses who participated in the trials felt that the additional time this took was “definitely worthwhile,” and an additional 25 percent felt the additional time was “probably worthwhile” (Hawes et al. 1995; Morris et al. 1990). Politically speaking, however, the most useful finding was that the majority of facility staff reported that using the MDS required them to spend more time speaking with residents and nursing assistants. All the facility nurses reported that this was valuable and should not be abandoned (Morris et al. 1990). The research team felt that framing the issue as one of giving residents a greater voice in their care would defeat any possible opposition to the plan.

## **Feasibility**

Feasibility was also a critical issue. CMS and the project team felt that if the system were not feasible for use nationwide by a wide variety of facilities and in a wide variety of policy environments, it would lose political support. Enhancing the feasibility of the assessment process involved several tactical decisions aimed at maintaining political support for the RAI. These included the following:

- Recognizing that there were very different policy environments and practice patterns across the country, the team decided to conduct field tests in a wide range of facilities (differing in size, staffing, and ownership) and in states with differing regulatory climates and with different Medicaid payment rates. The states in which trials were conducted—Connecticut, Massachusetts, Minnesota, North Carolina, Ohio, and Tennessee—were specifically selected because of the variability of average RN staffing in their facilities and their average Medicaid rates above and below the national median (Hawes et al. 1995).
- In addition, the research team felt the RAI system had to be feasible for the average nursing home. This meant that the assessment and care planning decisions in the MDS and RAPs had to be amenable to use by the type of staff found in the average nursing home. At the time, most U.S. nursing homes did not have geriatric nurse practitioners on staff or ready access to geriatricians or geropsychiatrists. This affected the content of the RAPs to some degree, limiting the team’s ability to specify what might be the most effective assessment strategies and interventions.
- Further, the project team did not require that facilities use multidisciplinary assessment teams, even though they viewed this as the most effective process. The RAI development team concluded

that the critical task was to specify the result that was expected—a comprehensive, functional assessment—and that, within certain limits, it should allow facilities to determine the processes that would produce this result.<sup>11</sup> The requirement for interdisciplinary assessment and care planning teams had proved to be a serious impediment to the Carter administration’s proposal, and the research team recognized that some facilities would clearly have a difficult time implementing any requirement for multidisciplinary teams. But the most compelling reason for not requiring interdisciplinary teams was the lack of conclusive empirical evidence at the time that multidisciplinary team assessment was essential to achieving accurate and comprehensive information. Indeed, the reliability trials indicated that one registered nurse who interviewed staff across all relevant disciplines could produce an accurate and comprehensive assessment of a resident’s status. Thus, while the RAI development team preferred interdisciplinary teams, it did not have sufficient evidence to mandate their use, especially given the tactical considerations against adding such a requirement.

- Finally, the research team sought to achieve a high level of inter-rater reliability for the MDS in settings in which time constraints were a reality. Early field tests revealed that staff did not have the time to refer to a user’s manual very often. The reality of low levels of training and continuing education for staff, combined with high staff turnover in nursing homes, presented serious challenges, and the research team felt that it might be overly optimistic to assume that all facility staff would attend adequate training sessions or consistently use the manual to clarify definitions or instructions. The project team therefore concluded that the best safeguard for effective operational use of the assessment system would be to include as much information as possible on the MDS form itself about the meaning of items, response codes, and key assessment instructions (e.g., the relevant assessment time frame).

Many of these decisions protected the RAI during the process of development and the early stages of implementation. Although the nursing home industry had participated in the Coalition for Quality Care and supported the OBRA ’87 legislation, some segments of the industry lobbied CMS heavily during the RAI development phase.

For the first several months of development, staff from the American Health Care Association (AHCA) and a group representing the major proprietary nursing home chains met at least monthly with CMS. In these meetings, industry representatives argued that the MDS went far beyond what Congress had envisioned when it enacted OBRA ’87. They asserted that a “minimum” data set would consist of a few items with simple “yes” or “no” response categories rather than a five-page instrument with some 300 assessment items. These industry representatives continued to assert that CMS should cancel the project or at least circumscribe the latitude given to the RAI research team by limiting the size of the instrument to no more than two dozen or so items. CMS, however, held firm, mollifying the industry representatives by continuing to meet with them and assuring them that their concerns would be taken into account. Meanwhile, the development and testing process continued without interference.

Eventually, the industry representatives brought these meetings to a halt, largely because of the very positive reports they were receiving from their clinical staff who were members of the advisory committee or who were participating in the clinical workgroups. The field testing process, the generally positive responses of facility staff to the instrument, and the responsiveness of the research team to suggestions from facility staff, advisory committee members, and other clinical reviewers helped allay provider fears. Moreover, some of the large, multistate chains came to recognize the benefit of a uniform nationwide assessment system, which would eliminate many of the varying state requirements with which they had to contend. None of this would have been possible, however, without the support of many within CMS, both at the time of implementation and in subsequent years, who understood the clinical utility of the RAI as well as other potential uses for the MDS data. Such uses included generating quality indicators from data gathered in the survey process. In addition, other CMS bureaus were already working on proposals to use RAI data for determining residents' eligibility for Medicare-covered skilled nursing facility benefits and for determining Medicare and Medicaid payment rates based on resident acuity.

#### **OUTCOME: EFFECTS OF THE RAI AND OTHER OBRA '87 PROVISIONS**

The early effect of these reforms on nursing home residents' quality of care and quality of life was impressive. During the first three years of implementation of the RAI and other OBRA '87-mandated federal regulations, several studies found significant improvements in quality of care and resident outcomes. The most striking improvements were the substantial reductions in the inappropriate use of physical restraints and psychotropic drugs (see, e.g., Garrard, Chen, and Dowd 1995; Hawes et al. 1997; Kane et al. 1993). CMS had concentrated on these areas in its implementation activities, which included providing training to surveyors and a heightened focus on these issues in the survey process. In addition, the mandated resident assessment processes associated with the RAI focused on reducing the use of physical restraints and on identifying psychotropic medication use that had a significant negative effect on residents. There was widespread acceptance of these changes in practice patterns among the provider community.<sup>12</sup>

CMS also commissioned an evaluation of the effects of the RAI as part of the contract for its development.<sup>13</sup> This quasi-experimental study used a complex, multistage, probability-based sample design, with cross-sectional and longitudinal data collected before (1990) and after (1993) implementation of the RAI for two independent cohorts ( $n > 2,000$ ) of residents in a random sample of 254 nursing facilities in ten states (Fries et al. 1997; Hawes et al. 1997; Mor et al. 1997; Phillips et al. 1997).

The CMS-funded evaluation and other independent studies found significant improvements in a variety of other process quality measures. These included both decreases in bad practices, such as use of indwelling urinary catheters and physical restraints, and increases in good practices, such as accurate medical record-keeping, comprehensive care plans, advance directives, toileting programs, and activities for residents (Hawes et al. 1997; Marek et al. 1996; Teno et al. 1997). One study also

found improved resident outcomes after implementation of the OBRA '87 regulations, with reductions in the rate of decline among elderly residents in such areas as physical and cognitive functioning and continence (Phillips et al. 1997). Consistent with this finding, there was also a significant reduction in hospital admissions of nursing home residents. (Mor et al. 1997).

These empirical findings of improved quality were supported by the reports of facility nursing staff and administrators who were surveyed about the RAI's effects on quality. For example, significant majorities of administrators and directors of nursing homes reported that the MDS, RAPS, and training manual had improved the quality of assessment, problem identification, and care planning in their facilities (Hines et al. 1994; Marek et al. 1996). The positive effects of the RAI and other aspects of the OBRA '87 nursing home reforms were also presented in testimony before members of the U.S. Senate by state and federal surveyors, ombudsmen, facility owners, medical directors, residents' family members, researchers, and the CMS administrator (U.S. Senate 1995; Vladeck 1995).

Although the evaluations of various aspects of OBRA '87 all pointed to significant improvements in quality, whether measured as changes in the process of care or in resident outcomes, the improvements were not universal (Fries et al. 1997; Hawes et al. 1997; Phillips et al. 1997). In addition, many observers have argued that quality of care in the nation's nursing homes started to decline again after the mid-1990s or have noted significant remaining quality problems (IOM 2000; U.S. GAO 1998, 1999a, 1999b, 1999c). These realities illustrate the difficulty of sustaining reforms and achieving permanent and widespread improvements in quality of care and quality of life in nursing homes.

#### **SUSTAINABILITY: WHAT ARE THE PROSPECTS FOR THE INTERVENTIONS AND OUTCOMES DISCUSSED ABOVE?**

Whether or not the RAI will survive and the positive effects of OBRA's implementation persist depends on forces at least partially exogenous to the nursing home industry. In this section, we identify the factors that suggest that the RAI, other OBRA '87 reforms, and their positive effects are likely to survive despite their continued susceptibility to reversal. The incident that best exemplifies the difficulty of sustaining regulatory reforms is the 1995 proposal to block-grant Medicaid. This episode demonstrated the political vulnerability of the RAI and other OBRA '87 reforms and the underlying factors that make nursing home reforms difficult to achieve and even harder to maintain over time, but it also illustrates how research can be used to influence public policy.

#### **A Changed Political Environment**

In 1994, the Republican Party won a majority of state governorships and took control of the U.S. Congress from the Democrats. Republicans embraced new House Speaker Newt Gingrich's (R., GA) "Contract with America," which, among other things, emphasized deregulation and shifting control from the federal government to the states.

The first shot at the OBRA reforms came from the National Governors Association (NGA) in January 1995. The NGA, now comprising 32 Republicans, 17 Democrats, and 1 Independent, adopted a Medicaid policy position that criticized OBRA '87 for placing the federal government in the position of “micromanaging the nursing home program” (Pear 1995a). Congress followed suit in March, with committee chairs floating the idea of giving responsibility for nursing home regulation to the states. This was an attractive idea in the context of recreating Medicaid as a program of block grants to states and, in the process, enabling the balancing of the federal budget by 2002 while still paying for the tax cuts being proposed by House Republicans (*National Journal's Congress Daily* 1995a). Under the block-grant proposal, states would receive fewer federal Medicaid dollars but would enjoy greater authority over how those dollars were spent. State governors would likewise have greater autonomy to set and enforce quality and staffing standards for nursing homes. This notion appealed to the many governors who viewed Medicaid expenditures on nursing homes as the “black hole” of state Medicaid budgets.

A successor to the Campaign for Quality, known as the Long-Term Care (LTC) Campaign, was formed to fight these proposals (*National Journal's Congress Daily* 1995b). Of the 141 groups represented by the campaign, most had a general interest in Medicaid policy but only a secondary or tertiary interest in nursing home quality (these included AARP, the Alzheimer's Association, the American Public Health Association, and the AFL-CIO). The NCCNHR was one of the few member-groups for which the OBRA '87 regulations were a primary concern.

The campaign initially focused on getting one or more of the key congressional committees to back away from Medicaid block grants and from eliminating federal regulation of nursing homes. This effort met with little success. Proposals to give the states authority and control over Medicaid continued to be made, without any public hearing at which resident advocates could present their views about the likely impact of this policy on nursing home quality. Even opposition from the White House, voiced at the 1995 White House Conference on Aging, did not affect Congress.

In the fall of 1995, the House passed the Medicaid Transformation Act, which would have repealed Medicaid and recreated it as a block-grant program. It replaced the OBRA '87 federal regulations with meager requirements that essentially eliminated federal regulation and allowed states to establish and maintain standards for nursing homes. This would have meant the end of the RAI and would have effectively rolled back standards to a situation with greater variability and even fewer constraints than the pre-1987 situation so roundly criticized by the decades of state and federal studies.

Consumer advocates were stymied. The House held no hearings on the bill's nursing home provisions, and the LTC Campaign seemed unable to find a meaningful public forum at which to present its views. The campaign's hopes rested on Senate reversal of the House's dismantling of the federal regulations governing nursing homes, but there was no comprehensive strategy for achieving this outcome.

At this point, the research community became a key player in the policy debate. Members of the research community entered into discussions with the public policy staff of the Alzheimer's Association and other members of the LTC Campaign, particularly AARP and the NCCNHR. These

discussions focused on the important role that the positive evidence concerning the effects of OBRA '87 might play in any debate over abandoning the nursing home reforms.

These discussions made it clear that research findings about the effects of the RAI and other OBRA '87 provisions could be useful adjuncts to testimonials from family members and resident advocacy groups. The policy experts from these organizations noted that the research findings would lend both scientific legitimacy and the weight of numbers to anecdotal stories from family members and providers. Members of the LTC Campaign worked with Senate staff to set up three hearings at which research findings were presented along with testimony from family members, consumer advocates, providers, ombudsmen, state regulatory agency staff, and the CMS administrator (U.S. Senate 1995; Vladeck 1995).

It also became clear that research findings had to be presented to policymakers in a less technical way than that demanded by peer-reviewed journals and that, in this era of fiscal constraint, researchers had to address the cost implications of study findings. The RAI development and evaluation team, for example, had found that, against all expectations, hospital use by nursing home residents declined after the implementation of the RAI and other OBRA '87 provisions, with no increase in mortality. To make this finding more salient to legislators, the research team extrapolated the study's result to the nursing home population as a whole. They used data from 1993 (the year the reduction was observed) to estimate the overall fiscal impact of the decreased hospital use. (Researchers assumed that such reductions, observed in the 254 selected facilities in 10 states studied in 1993, would be repeated nationwide.) A 25 percent reduction in hospital use by nursing home residents would, they estimated, yield a \$2 billion savings on Medicare-reimbursed inpatient stays alone, not counting any of the expenditures associated with patient copayments, ambulance costs for transportation, or any subsequent post-acute care. This estimate was particularly important because it addressed assertions by the NGA and House leaders that the OBRA '87 regulations were expensive and counterproductive (*National Journal's Congress Daily* 1995b; Pear 1995a).

It also became apparent that science could affect policy if research findings were used to “redefine” the problem. Initially, both the NGA and the House Republicans defined the problem within the context of their perceived electoral mandate for the “Contract with America,” one part of which emphasized deregulation, reliance on market forces, and shifting as much control as possible from the federal government to the states. As has been indicated, the effort to end the OBRA '87 reforms and federal regulation of nursing homes was caught up in a larger effort to reduce the budget and block-grant the Medicaid program—and thus in the battle between the Republican and Democratic parties. The Democrats tended to portray the House Republicans’ “Contract with America” and their plan to block-grant Medicaid as an attempt to provide tax cuts for the wealthy at the expense of the most vulnerable members of society. Some moderate Republicans in the Senate joined the Democrats in expressing opposition to ending federal regulation of nursing homes, but these opponents did not really *redefine* the issue so much as state their opposition to moving responsibility from the federal government to the states. As a result, the nursing home issue did not initially generate much public attention or political heat.



The research community was able to help redefine the issue in several ways. First, most of the IOM members sent a letter to members of Congress. The letter noted that overturning OBRA '87 and giving regulatory responsibility back to the states would amount to returning to the pre-1987 situation that the IOM committee and scores of state reports had repudiated. The letter emphasized that the variability in state regulation would bring poor quality and inadequate regulation back to many nursing homes. And the letter briefly summarized research findings about the positive effects of the OBRA '87 nursing home reforms on quality of care and quality of life for residents.

Second, in their testimony and in speaking with the press, researchers translated what they believed to be the most significant findings about OBRA '87 into human terms. For example, one researcher took the quantitative finding about the magnitude of restraint reduction and converted that into the number of elderly nursing home residents who, as a result of OBRA, could be untied or never restrained at all—a total of 250,000 people each year (Hawes 1995).

Third, researchers helped the LTC Campaign and Senate supporters redefine the issue of nursing home deregulation from that of ending “federal micromanagement” and of “freeing states to make relevant decisions” to one of diminishing nursing home quality. Key researchers and former IOM committee members spoke to the press as part of this attempt to refocus the debate by redefining the issue. In both press interviews and in testimony before Congress, the researchers specifically countered the arguments about “over-regulation” and shifted the focus to quality of care and the well-being of residents.

For example, in an interview with a reporter for the *New York Times*, Rep. Thomas J. Bliley, Jr. (R., VA), chair of the House Commerce Committee, asserted that Congress intended to “end an eight-year experiment with federalization of nursing home standards. . . . By all accounts . . . the Washington-run nursing home regulation has been a bureaucratic nightmare: confusing, expensive and counterproductive” (Pear 1995a). But members of the LTC Campaign gave the reporter the names of three researchers whose empirical findings contradicted Bliley’s assertion. An IOM committee member told the *Times* that ending federal regulation would cause a significant reduction in quality and be a significant step backward. Another IOM committee member called the proposal “a return to the bad old days.” A researcher told the reporter that the OBRA reforms were “paying off,” slowing rates of decline among residents and reducing their hospital use, saving an estimated \$2 billion annually on acute care. These themes were picked up in a piece by syndicated columnist Ellen Goodman, who wrote a scathing column entitled “Remaking the Nursing Home Horror Tale” (Goodman 1995).

Democratic and moderate Republican Senators echoed this focus on the positive effects of OBRA '87 and the RAI in subsequent floor debates and newspaper interviews (Carlson 1995; Kennedy 1995; *National Journal's Congress Daily* 1995b). Thus the debate in the press and among supporters shifted away from arguments about “federal micromanagement” and freeing the states to protecting the elderly and preserving improvements in nursing home quality.

The success the advocates were having in redefining the issue clearly had an effect. In floor debates in both the House and Senate during the fall of 1995, Democrats and moderate Senate Republicans

increasingly cited nursing home quality issues and ending OBRA '87 federal regulations as serious stumbling blocks to passage of the House budget bill. Many Democrats made the issue a major argument for rejecting the entire Republican budget proposal. Indeed, President Clinton subsequently cited the need to retain federal nursing home standards as part of his rationale for vetoing the initial budget bill.

The issue of abandoning the OBRA '87 federal standards and the adverse impact this would have on quality became a lightning rod, attracting increased attention to the split between Republicans and Democrats. Moreover, the negative press the issue generated spilled over to Republican proposals on Medicaid block grants, the budget bill, and tax cuts. Columns such as Goodman's "Remaking the Nursing Home Horror Tale" and Margaret Carlson's *Time* magazine piece "Back to the Dark Ages" (Carlson 1995) were matched by articles on the nursing home issue in most major national newspapers, following the lead of the *New York Times* and *Washington Post*. Sen. Robert Dole (R., KS), then the Republican majority leader, complained on the Senate floor about the attention the nursing home reform issue was getting: "I know there is a lot of politics about nursing homes. I know the liberal media bought into the spin put on by Democrats" (Dole 1995).<sup>14</sup>

As a result of the redefinition of the issue and the attention it was attracting, the Senate reversed its original concurrence with the House budget bill and retained the nursing home standards. This was done in part because moderate Senate Republicans joined the Democrats on the issue of nursing home regulation. They threatened to vote against the entire budget bill unless the federal OBRA '87 standards were retained. Some observers also felt that Dole, who at the time was running for the presidency, agreed to retain the OBRA '87 reforms in order to "deflect criticism from Democrats and deprive them of political issues that could be used in [the] elections" of 1996 (Pear 1995b).

In any such web of political machinations, it is always difficult to determine the exact, or even approximate, weight to give to individual events or factors. Some might argue that the Democrats and moderate Senate Republicans would have carried the day without the aid of policy-relevant research. Arguably, they could simply have raised the specter of reductions in quality, paraded a long line of consumer horror stories before reporters and their congressional colleagues, and carried the day in that fashion. The point here, however, is not whether the availability of policy-relevant research was the deciding factor. It is simply the recognition that those involved in a policy struggle and those reporting on that struggle saw science-based evidence as a very relevant element in the policy debate and used it vigorously to what seems to have been good effect.

### **Implications for the Future Sustainability of the RAI**

The near-death experience suffered by the RAI and other OBRA '87 reforms in 1995 demonstrated that regulations that impose on the latitude of providers are always vulnerable. In this case, consumer advocates and their allies in Congress successfully resisted a major change.

A struggle over the CMS regulations implementing OBRA '87 mandates on enforcement was going on at roughly the same time as the battle over block-granting Medicaid and nursing home regulation.

The nursing home industry, particularly AHCA, strongly opposed full implementation of the enforcement provisions, and their implementation had been delayed for nearly five years after the other major OBRA '87 regulations had gone into effect. Consumer advocacy groups tended to view this as a betrayal, and AHCA's executive director classified both the delay of the enforcement regulations and their promulgation in 1995 as major victories (Edelman 1997–98; Pear 1997; Weissenstein 1997).

In fact, AHCA had extraordinary access to the Clinton White House. As was noted earlier, a prominent AHCA member chaired the Democratic Party's Business Council and became the party's finance chairman. At the same time, nursing home interests contributed more than \$1.1 million to the 1996 Clinton campaign (Weisskopf 1997). Given this reality, many within the CMS bureaucracy felt that the delay in implementation and other actions consumers viewed as "watering down OBRA" were in fact necessary to save both other provisions of OBRA and the key elements of the enforcement provisions.

What these episodes illustrate is that regulation remains a politically charged area of public life in the United States. Thus it remains an open question whether all the provisions of OBRA '87 are sustainable. Indeed, they seem particularly vulnerable when reductions in government spending and constraints on Medicaid are central issues in Washington and in the states. Further, the staffing shortages currently experienced by many nursing homes nationwide not only endanger the ability of facilities to deliver high quality care, but they also provide fodder for the debate over whether regulations are excessive.

The regulations that appear to be most sustainable are those that represent what consumers and providers identify as directly clinically relevant and helpful. For example, provider and consumer support for reducing the use of physical restraints remains widespread and strong, and few would advocate a repeal of the requirement on restraint use. Similarly, consumer advocates tend to have a very positive view of the RAI, and providers argue that the MDS has been one of the most effectively implemented of the OBRA '87 regulations. Even most administrators and directors of nursing who complained about the paperwork burden associated with the MDS acknowledged that the RAI had improved their ability to plan care and monitor the effects of interventions (Hines et al. 1994; Marek et al. 1996).

Two other factors add to the long-term sustainability of the RAI. First, many homes are using MDS data in quality improvement initiatives to understand their resident case mix, and for management (e.g., in projecting staffing needs for different units), and many nursing home chains find MDS data useful for management purposes and prefer the uniformity of requirements across states associated with a federally mandated instrument. Second, many states and the Medicare system itself have incorporated the use of MDS data into their payment and regulatory systems, making the MDS data even more central to facility operations.<sup>15</sup>

As a result of these factors, the RAI is likely to survive. It will, however, be subject to continued attacks as "an excessive paperwork burden." If advocates of the RAI do not recognize this threat and neglect to redefine the issue in terms of the RAI's effect on the quality of care and life experienced by residents, the RAI will be vulnerable to attack.

The RAI faces three other potential impediments to its sustainability. One arises from a new federal requirement for uniform data reporting elements across all post-acute care programs. Currently, different instruments are used for reporting patient-level data in home health (Outcome and Assessment Information Set, or OASIS) and nursing homes (RAI/MDS). The issue of what will be required for rehabilitation facilities remains undecided. The initial split between OASIS and the RAI occurred, in part, because different branches of the CMS bureaucracy were charged with the development and testing of the home health and nursing home instruments. Unlike the RAI, the OASIS instrument is not intended as a comprehensive assessment that can be used to generate a care plan; it is only intended to produce indicators of the quality of an agency's performance. There has been some agitation about the CMS mandate for two different instruments by states that want uniformity of instruments and data elements across all long-term care settings and prefer the RAI/MDS to be the core of any assessment program. CMS has not resolved the issue by moving to one basic instrument, however, and such a move toward real uniformity seems unlikely. The development of a "crosswalk" formula that allows comparisons between OASIS and MDS data items seems a more likely outcome.

Another potential threat to the sustainability of the RAI involves the lack of attention it has generated among physicians, as well as some physicians' opposition to some OBRA '87 provisions. The American Medical Directors Association (AMDA), which represents nursing home medical directors, has been supportive of both the RAI and other OBRA '87 requirements (Russell 1995), but other groups, notably the American Medical Association (AMA), have largely ignored the RAI. Even during the RAI development process, the official AMA representative was only an occasional attendee at the national advisory committee meetings and did not participate in the clinical workgroups. In part, this may reflect the traditionally low salience of issues related to nursing home care for most physicians, but it may also be a reflection of physicians' general antipathy toward any system that attempts to improve quality through the use of uniform guidelines, which some physicians regard as "cookbook medicine" (McGlynn and Brook 2001). Some physicians, for example, have been particularly critical of OBRA '87's attempt to reduce inappropriate use of psychotropic medications, arguing that this regulatory initiative infringes on their ability to prescribe medications that best address the needs of individual patients. Finally, some geriatricians have criticized the RAI because it does not contain some of the items they need for particular quality measures for specific medical conditions. Despite these factors, the objections of academic geriatricians have little practical impact on the RAI's sustainability. Just as they were not involved in the development process, so most physicians (other than nursing home medical directors) have remained aloof from the politics surrounding OBRA '87, and the medical directors have been generally supportive of both the RAI and OBRA '87. The real potential harm to the RAI comes from most physicians' lack of knowledge about how to use the MDS data effectively to evaluate changes in their patients and what they can do to ensure greater accuracy of assessment by facility staff.

Finally, yet another threat to the RAI emerges from the argument advanced by some observers that the MDS data are not reliable. Granted, the field trials demonstrated that facility staff members

were able to produce assessments that were reliable across assessors (Hawes et al. 1995; Morris et al. 1990), and the evaluation found that there had been an overall improvement in the accuracy and comprehensiveness of information in residents' medical records after implementation of the RAI (Hawes et al. 1997). And in a similar vein, some state Medicaid agency evaluations found that facility assessment data were, on average, accurate (Boulter 1995; Jobe 1995). Despite this, concerns about shortages of registered nurses, high staff turnover, limited training, and facility commitment have translated into disquiet about the accuracy of the MDS data provided by facilities (Harrington et al. 1997). Whatever the reality of facility performance, it is difficult to attribute the problem to the RAI. If facilities do not adequately train staff or put needed assessment practices in place, and if state regulatory agencies do not insist on accuracy, the problem will continue to exist, regardless of the nature of the instrument.

## **LESSONS**

Two different kinds of lessons have emerged from the RAI's history: lessons related to the development and implementation of reforms and lessons about regulatory reform and the politics of the policy process.

### **Implementation Lessons**

Many of the lessons about developing and implementing legislative reforms emerge from the decisions made by CMS and the research team during the development and testing of the RAI. These important decisions have contributed to the clinical utility and political viability of the instrument and the assessment system. Some lessons about what might have been done differently have also emerged over time. Among the implementation-related lessons are these:

- It is probably impossible to achieve comprehensive quality reform without adequate staffing in facilities. The IOM recommendations and the resulting OBRA '87 nursing home reforms failed to adequately address issues related to nursing home staffing. They gave no recommendation on staffing levels, other than minimums for licensed staff. For example, the issue of staff-to-resident ratios for certified nursing assistants, who perform an estimated 80 percent of the hands-on care in nursing homes, was largely ignored. As a result, most nursing homes implemented the OBRA '87 reforms without increasing their staffing levels for direct-care staff. These levels were already too low in the early 1990s, and the problem has intensified as many facilities experience difficulty in hiring and retaining sufficient staff even for inadequate staff-to-resident ratios.
- More attention needs to be paid to training. The research team wrongly assumed that the national and state associations, in conjunction with the state regulatory agencies, would offer high-quality, ongoing training in assessment and care planning to facility staff. Unfortunately, this did not occur uniformly across the United States. Indeed, too much of the training that was

- provided concentrated on the minutiae of “filling out the MDS form.” What was needed was more training in how to link the MDS data to the RAP guidelines, a process designed to identify treatable causes of functional deficits and risk factors for decline that could be addressed in a well-specified and executed care plan. Sadly, many of the staff working in long-term care lack the time or knowledge to use the assessment data to develop and implement an effective care plan. (Italy provides a different lesson—one that other countries might follow. In at least one region, Italian nursing homes have used the RAI and RAPs as part of a comprehensive effort to educate clinical staff working in long-term care about geriatrics and about linking assessment information to effective care-plan interventions for nursing home residents.)
- More attention should have been paid to ensuring that administrative staff, including directors of nursing, understand more about the potential multiple uses of the MDS data. Once administrators understand that they can rely on the data for a variety of purposes—from evaluating care interventions, to allocating staff resources, to benchmarking their own facilities’ performance—they should have a greater commitment to ensuring that the data are accurate. Some training efforts should therefore have focused more directly on how facility administrative staff can use the MDS data to plan, manage, and evaluate more effectively.

### **Policy-Reform Lessons**

The passage of the OBRA '87 nursing home reforms and the subsequent implementation of the RAI, as well as their near-repeal, reveal some important lessons about attempts to improve quality in American nursing homes:

- Legislation, rather than administrative action, may be needed for comprehensive reforms. Because of the highly politicized nature of regulation in American politics, all regulations, even those aimed at improving quality, are subject to the vagaries of changes in administrations and their priorities. Legislative mandates are more difficult to abandon. Even when originally enacted with bipartisan backing and strong support from consumers and providers, however, legislated changes in federal rules governing nursing homes remain politically vulnerable, particularly if they are caught up in another, broader political agenda.
- Reform is more likely when the bureaucracy charged with promulgating and implementing the regulations views the changes as consistent with its mission. Equally important, the implementation should be carried out in a way that does not endanger the bureaucracy by arousing the ire of the nursing home industry. Efforts to create consumer and provider “buy-in” to changes in regulation—and to maintain that enthusiasm over time—are essential and well worth the effort.
- Research can play a critical role in policy formation and implementation. For the last three decades, efforts to reform nursing home care have had a history similar to that of efforts to address a host of other social problems. Such problems are only episodically the focus of

significant attention from the public, the media, and legislative bodies, and they affect only limited numbers of people. Most people have not suffered from poor-quality nursing home care, and even groups that represent older people, such as AARP, do not place this topic high on their policy agenda—or at least not on a regular basis. Moreover, the cost of addressing the causes of poor quality is likely to be substantial. In such a situation, researchers can help maintain at least a low level of attention to the problem by consistently casting their results in terms of policy issues. They can also work to translate and communicate those findings in a meaningful way to consumer advocates and policymakers. Strategic thinking and planning can create “alarmed discovery” of the depth and seriousness of a problem—placing the issue higher up on the policy agenda and opening a window for incremental or comprehensive reform. And research can also lead to more effective regulations, particularly if it focuses on issues of clinical utility, feasibility of implementation, and cost impact.

- When “alarmed discovery” of a quality problem occurs, consumer advocates must recognize that their window of opportunity is limited. Using such an opportunity effectively demands rapid action to craft a coalition of interest groups and achieve consensus about the needed legislative or regulatory change. Consumer advocates should focus on research findings that identify practices and policies that promote quality and then use those findings to help redefine the issue as one of quality of care, not governmental regulation.
- Finally, policies that both consumer advocates and providers view as clinically relevant and achievable are more sustainable over time. It is therefore critically important to involve providers, along with consumers and clinicians, as partners in the development and implementation of quality initiatives.

## NOTES

- 1 Public policy governing nursing homes is largely a function of the federal standards set for participation in the two health care programs that are the primary payers for nursing home care, that is, Medicare and Medicaid. These programs set standards, specify inspection processes, and mandate enforcement remedies that apply to all facilities that participate in the programs and receive payment for the care of covered program beneficiaries. More than 95 percent of nursing homes participate in Medicare or Medicaid (Strahan 1997). Medicare is a federally funded program that covers acute, ambulatory, and rehabilitative care for the elderly, as well as for those nonelderly persons who are permanently disabled and meet program eligibility criteria. Medicaid is a combined federal and state program that covers specified health care services, including nursing home care for persons who are poor or, in many states, defined as meeting financial criteria for being “medically needy.” Because Medicare coverage is restricted to skilled, rehabilitative care, in 1998 it covered only 12 percent of expenditures on nursing homes. Medicaid accounted for 46 percent of the expenditures and helped pay for

- nearly 68 percent of the residents. The remainder of dollars spent on nursing home care came from out-of-pocket spending by individuals (33%) and other payers, such as private insurance and the Veterans Administration (9%). (The 68 percent of residents who are Medicaid-eligible contribute most of their monthly income—from Social Security and/or pensions—and Medicaid pays the remaining charges after their income is exhausted. This is why Medicaid is a payer for 68 percent of the residents but accounts for only 46 percent of the expenditures on nursing home care.)
- 2 For example, after Ohio led the nation in nursing home fires resulting in multiple deaths, the state legislature enacted mandatory sprinkler requirements (Ohio 1978).
  - 3 California’s “Little Hoover Commission” is a state oversight agency credited with issuing reports, such as a 1983 study of skilled nursing facilities (California 1983) that led to state reforms, including the creation of a system of citations and fines that put teeth in the regulatory system. New York’s Moreland Act Commission was created partly in response to scandals in facilities owned by Bernard Bergman and to concerns that the abysmal care and regulatory failures found in Bergman’s facilities were widespread. The series of reports issued by the Moreland Act Commission (New York 1975, 1976) led to some reforms in New York. Similarly, the Ohio legislature’s Nursing Home Commission (Ohio 1978) found and documented significant and widespread quality problems and followed with a blueprint for needed policy changes (Ohio 1979), a residents’ bill of rights, and two omnibus reform bills. The bill of rights and one reimbursement reform bill were enacted before the two-year commission expired, but the other omnibus quality improvement reform bill, which came to be known as “little OBRA,” was not enacted until 11 years later, following the passage of OBRA ’87 at the national level.
  - 4 As of 1995, 54 percent of U.S. nursing homes were owned by chains, a proportion that had increased from 41 percent in 1985 (Strahan 1997). This percentage is apparently holding fairly steady, with chain ownership at 55 percent in 1999. The ten largest chains controlled 19 percent of the facilities and 21 percent of the beds nationwide in 1999 (Vickery 2000).
  - 5 Many of these findings were echoed in a class action lawsuit, *Smith v. O’Halloran*, brought by nursing home residents in Colorado against facilities in that state as well as what is now the U.S. Department of Health and Human Services. The case, which went all the way to the U.S. Supreme Court, was decided in favor of the defendants. Among other things, the 10th Circuit Court ruled that the federal government had to substantially change the way it surveyed nursing homes. (*Smith v. O’Halloran*, 557 F. Supp. 289 [D. Colo. 1983], *rev’d* sub nom. *Smith versus Heckler*, 747 F.2d 583 [10th Cir. 1984].)
  - 6 Similarly, in Ohio, segments of the nursing home industry had defeated several proposals for a residents’ bill of rights. When a fifth bill was introduced, the for-profit trade association estimated that implementing a residents’ bill of rights would cost more than \$1.50 per resident per day. The staff of the Ohio legislature’s Nursing Home Commission estimated the cost at only a few pennies per resident day. To demonstrate their confidence in the estimate, commission staff asserted that



- they would perform all the notification, resident and family contacts, and hearing components of the bill for \$0.42 per resident day, and use the proceeds to fund the operation of the commission, including its fraud hearings, in perpetuity. The industry dropped its cost argument, and the bill was enacted by the Ohio legislature.
- 7 For the sake of clarity for present-day readers, we use CMS—the agency’s current designation—throughout this paper rather than Health Care Financing Administration (HCFA), as the agency was known during the period under discussion.
  - 8 Contract DHHS 500-88-0055 was from HCFA’s Health Standards and Quality Bureau (HSQB) for a project called *Develop the Resident Assessment System and Database for Nursing Homes*. The project team was led by North Carolina’s Research Triangle Institute and included among its subcontractors the Social Gerontological Research Center of the Hebrew Rehabilitation Center for the Aged (Boston), the Center for Gerontology and Health Care Research at Brown University (Providence), and the Institute of Gerontology at University of Michigan at Ann Arbor. The key investigators were Catherine Hawes, Brant E. Fries, Vincent Mor, John N. Morris, and Charles D. Phillips. Katharine Murphy was the lead nurse clinician, and Sidney Katz, M.D., headed the clinical panel. Key players at HCFA/CMS included Helene Fredeking, head of HSQB’s Office of Long-Term Care; Wayne Smith, head of HSQB during the development of the RAI; Bruce Vladeck, the HCFA administrator; and (sequentially) project officers Allan Friedlob, Elliana Steele-Friedlob, and Sue Nonemaker.
  - 9 The RAI system also includes a training manual, mandated quarterly review forms, and a form on which staff summarize decisions about care planning and note the location of any planned intervention. The RAI must be completed when the resident is admitted to the facility and annually thereafter, as well as any time there is a significant change in the resident’s status. The quarterly review contains a few key MDS items and is completed every three months, in the intervals between annual assessments.
  - 10 The advisory committee included representatives from nursing home trade associations, consumer advocacy groups, ancillary providers (e.g., mental health professionals, physical therapists), medical directors, nurses, social workers, and others viewed as key stakeholders. It also included representatives from state and federal agencies, including Medicaid agencies and state survey agencies.
  - 11 The RAI did specify that the facility’s assessment had to draw information from multiple sources, including interviews with residents and family members, direct observation of residents, interviews with direct-care staff across all shifts, and medical records.
  - 12 Some among the provider community had moved to reduce use of physical restraints prior to the enactment of OBRA ’87. The most notable example of this trend was the “Untie the Elderly” initiative sponsored by Kendall-Crossland, a group of nonprofit facilities in Pennsylvania. Although the idea was gaining acceptance among providers and staff, few facilities had actually implemented programs or achieved significant reductions before October 1990, when reductions

- were required by the new regulations (Hawes et al. 1997; Kane et al. 1993). The change in use of psychotropics was nearly as striking, and there is some evidence suggesting facilities began reducing the use of psychotropics between the passage of the OBRA '87 legislation and the effective date for implementation of the new regulations in 1990 (e.g., Hawes et al. 1997; Kane et al. 1993).
- 13 One issue that has been of concern to some commentators is the use of the development team for the evaluation. The obvious concern here is that the development team might be so invested in the success of the instrument that it might unwittingly fail to provide an unbiased evaluation. A number of factors make this theoretical concern one that is very unlikely to have operated in reality. First, the development team was committed to improving the quality of care and quality of life experienced by nursing home residents. Thus, like others, the team wanted to know whether the system worked as intended. More important, a number of external safeguards were in place. The evaluation design and analysis plan were reviewed and approved by a group of senior external researchers brought in by CMS to ensure that the evaluation would be scientifically sound. In addition, all the evaluation results were published in peer-reviewed journals, and thus faced careful scrutiny by anonymous reviewers. Finally, “objectivity” in research is not something achieved merely by separating development from evaluation. Developers can be scrupulous in their adherence to scientific norms and as objective as any other evaluators in their analyses of results, and any evaluator may bring a set of preconceived notions to the task. Similarly, the demands of clients can drive evaluations performed by anyone. Individual researchers—developers or evaluators—can be so wedded to a hypothesis that they unconsciously skew their observations. There are no easy structural remedies for this problem. In the end, good science demands that researchers adhere to the fundamental rules of scientific inquiry and that they let others review their design and results. Both these requirements were met by the RAI evaluation.
  - 14 Dole’s comment about the media “buying the spin” Democrats put on the nursing home issue may also have reflected the unhappiness of a politician who has had an issue redefined out from under him. Part of the problem was that the Republican leadership, having heard only from governors and the nursing home industry prior to the formulation of their Medicaid and nursing home proposals, was literally unaware of some of the context in which they were operating. That fact was borne out the following year when Sen. Trent Lott (R., MS), who succeeded Dole as majority leader, met with the CMS administrator and deputy administrator (both of whom had been on the IOM committee and had been active in the anti-repeal efforts in 1995). At that meeting, Lott cited the MDS, about which a constituent had complained to him, as a prototypical example of excess government paperwork and bureaucracy. He clearly had no concept that this was the very issue over which he and his colleagues had taken such a political beating just a year earlier.
  - 15 Another important aspect of the RAI—one that probably will not add to its appeal in a political battle—is that MDS data are available on all nursing home residents, not just those whose costs are covered by public payers. This makes the MDS data a powerful tool for policy analysts,

policymakers, and researchers interested in long-term care. Archived MDS data offer them a very detailed picture of the characteristics of the entire nursing home population in this country. The data can be used to generate quality indicators that can be used by facilities to identify areas for improvement or by state regulatory agencies to target surveys. In addition, these population data can be used to address a variety of issues beyond the reach of the traditional sample data collected in the National Nursing Home Survey or the Medical Expenditures Panel Survey. If a researcher wishes to investigate the needs and strengths of the nursing home population in isolated rural areas, for example, then only population data (or a very expensive and difficult primary data collection) will allow him or her to pursue such an analysis based on data from a meaningful number of residents.

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## **EXECUTIVE SUMMARY**

The concurrent pressures of public anxiety about the viability and quality of health care and persistent fiscal constraints place extraordinary demands on those who must make decisions about future directions of the Canadian health care system. The primary appeal of evidence-based decision making (EBDM) is the promise that objectivity, evenhandedness, and precision will replace arbitrariness, bias, and error. The goal of EBDM is to systematically integrate the clinical, managerial, and political expertise that a decision maker gains through personal experience with the best available evidence derived from research. Because the base of knowledge in health care is relatively new, limited, and very fluid, moving to an evidence-based approach to decision making is essential.

In reality, evidence-based decision making in health care often remains an optimistic ideal. Those who make health policy often find that there are no usable data to provide evidence on competing policy or managerial options. Even where evidence is available, decision makers may have insufficient expertise to effectively analyze or interpret data. The presence of data is not a sufficient condition for its translation into information and then knowledge the decision maker can act upon.

The experience of Ontario's Complex Continuing Care (CCC) hospitals and units provides a useful case study of the transition from anecdote-based to evidence-based decision making. Many gaps remain in the types of evidence about CCC available to policymakers, managers, and consumers, but the Ontario Ministry of Health's 1995 decision to mandate use of the Minimum Data Set (MDS) 2.0 represents an important step forward in building a foundation of evidence to support future decision making.

The 1993 Chronic Care Role Study recommended numerous improvements in service delivery to enhance the partnership between CCC hospitals and units and long-term care facilities (nursing homes and homes for the aged). The study report recommended that CCC hospitals and units target a medically complex patient population and serve as centers of excellence for research and education related to the needs of persons with complex and/or unstable chronic illnesses. The report also noted that CCC systems for assessment of needs, classification for funding, and tracking outcomes were inadequate. To address this problem, the Ontario Ministry of Health mandated that all CCC hospitals and units in the province assess patients with MDS 2.0.

In the spring of 1996, the provincial government introduced legislation that led to creation of the Health Services Restructuring Commission (HSRC). The fundamental purpose was to initiate major change in the organization and provision of health care services in Ontario, and in Ontario hospitals in particular. The HSRC was an apolitical body charged with making decisions ranging from restructuring hospitals to recommending to government changes in other elements of the health services system.

The HSRC's 1998 report distinguished between long-term care beds and CCC beds based, at least in part, on Resource Utilization Group, Version III (RUG-III) categories from the MDS 2.0, with patients in the Clinically Complex, Extensive Services, and Special Care levels generally designated for complex continuing care and those in the Behaviour Problems, Impaired Cognition, and Physical

Functions Reduced categories designated for long-term care. Responding to a lack of evidence to guide its decision making, the HSRC also recommended the development of an accountability framework with “a single point of access” as well as the “adoption of a unified classification system for determining eligibility and placement into LTC [long-term care] facilities (including complex continuing care beds)” based on the MDS instruments.

Two years after the mandated implementation of the MDS in CCC, decision makers began to use these data to support policy development. In 1998, the Ontario Ministry of Health and Long Term Care accepted a recommendation that RUG-III be used as the basis for funding Complex Continuing Care. The ministry charged a provincial working group with developing operational recommendations for the funding methodology Ontario should use to translate RUG-III scores and other information into a payment system for CCC. That system is now used to set CCC hospital budgets in Ontario. An MDS Quality Network was established through the leadership of CCC hospitals. In addition, the Canadian Institute of Health Information (CIHI) commissioned a series of annual reports on the quality of care in Ontario CCC hospitals and units. In 2001, the Ontario Hospital Association (OHA) released its first balanced scorecard for CCC, making heavy use of MDS 2.0 data for the financial and clinical indicator quadrants.

In many ways, Ontario’s implementation of the MDS in CCC hospitals and units has been reasonably successful. This success, however, has been dependent on a number of essential conditions, and some challenges remain to be addressed. Among the key lessons learned from Ontario’s experience in implementing a standardized CCC assessment system to support evidence-based decision making are these:

- Evidence is an essential ingredient for change. The challenge faced by the HSRC was more difficult because of the paucity of data.
- It takes effort to get good data. Ongoing training and monitoring of data quality are needed at all stages of implementation.
- Feedback is a key ingredient to sustaining the adoption of information systems.
- Sometimes change must be mandated. Both the implementation of the MDS and the experience of the HSRC exemplify the need for strong political support of systemwide organizational change.

## **INTRODUCTION**

The viability and quality of the health care system is a central concern for Canadians. Between 1991 and 2000, the proportion of Canadians rating the health care system as excellent or very good declined from about 60 percent to about 25 percent (Canadian Institute for Health Information 2001). Canadian seniors were less likely than their counterparts in the United States, New Zealand, and Australia to rate the medical care they received as excellent, and about one in five felt the system needs to be rebuilt (Schoen et al. 2000). For Canadian policymakers and service providers, management of health expenditures is an important priority. Between 1990 and 2000 health

expenditures rose from 9.0 percent to 9.2 percent of gross domestic product and from \$2,181 to \$3,152 per capita (Organization for Economic Cooperation and Development 2002). The concurrent pressures of public anxiety about health care and persistent fiscal constraints place extraordinary demands on those who must make decisions about the future direction of the health care system.

The catchphrase *evidence-based decision making* (EBDM) currently permeates clinical practice, policy development, and management in health care in Canada and abroad (Geddes and Carney 2001; McKibbin, Eady, and Marks 1999; Muir Gray 1997). The primary appeal of EBDM, promoted by Sackett and colleagues (1997) and others, is the promise that objectivity, evenhandedness, and precision will replace arbitrariness, bias, and error in decision making. The goal is to systematically integrate the clinical, managerial, and political expertise that a decision maker gains through personal experience with the best available evidence derived from research. Because the base of knowledge in health care is relatively new, limited, and very fluid, moving to an evidence-based approach to decision making is essential.

Health care is becoming increasingly complex. The needs of the populations served are in constant flux. Competent decision makers must be able to

- Frame the questions that must be answered in evidence-based terms
- Access relevant, timely, valid, and reliable data
- Evaluate evidence from multiple perspectives
- Apply judgments about that evidence directly to their current experience

The wide availability and use of microcomputers in the 1980s and development of the Internet in the 1990s marked the onset of the so-called Information Age. The number of scientific journals devoted to health care—both print journals and electronic publications—has exploded. There is the expectation that evidence, if not knowledge, is now at everyone’s fingertips, simply awaiting the entry of the right set of key words in a favorite search engine. With the *evidence-based* part of the formula taken care of, decision making should be easy—or so the thinking goes.

The reality faced by health care decision makers is usually far from this optimistic ideal. First, the absence of universally accepted data standards raises the question of the comparability of one study to another. Evaluating the evidence is difficult, and it will remain so until appropriate standards are put in place and adhered to throughout the spectrum of professions, organizations, and institutions that make up the health care “system.” Moreover, other issues will continue to affect decisions no matter how compelling the evidence. Personal perspectives, local preferences, cultural differences, political objectives, and other evidence-independent factors will not go away. Decisions may be evidence-based in part, but they will almost certainly also be values-based (Hunter 2001; Smith 1989).

A further problem is that policymakers, managers, and clinicians may have insufficient expertise to analyze data and interpret findings effectively. Those who would practice EBDM must be able to do more than simply retrieve evidence; they must also be able to evaluate it and weigh its merits against other evidence that may point in different directions. As Sackett and colleagues (1997) and Muir Gray (1997) note, this requires a union of analytic skills, substantive knowledge, and judgment that draws from professional experience without being limited by it.

It is not uncommon for health policymakers to find that there are simply no usable data providing evidence for competing policy or managerial options. To give but one of myriad potential examples, the absence of national, standardized data makes it virtually impossible to draw any inferences about the cost-effectiveness, quality, or outcomes of community and institutional services for the elderly and persons with disabilities in Canada (Advisory Council on Health Infrastructure 1999).

The experience of Ontario's Complex Continuing Care (CCC)<sup>1</sup> hospitals and units provides a useful case study of the transition from anecdote-based to evidence-based decision making. Numerous gaps remain in the evidence about CCC available to policymakers, managers, and consumers, but the Ontario Ministry of Health and Long Term Care's 1995 decision to mandate use of the Minimum Data Set 2.0 (MDS 2.0; see Morris et al. 1997) represents an important step forward in building a foundation of evidence to support future decision making (Hirdes and Carpenter 1997).

## **THE EVOLUTION OF EVIDENCE IN COMPLEX CONTINUING CARE**

Ontario is Canada's most populous province, with 11.7 million people. About 13 percent of its population is aged 65 and over. It is one of the few provinces in Canada to provide hospital-based care for the frail elderly who are not in the acute phase of illness. Through the early 1990s, persons requiring long-term institutional care received it from a mix of facilities, including

- Chronic care hospitals (as they were then called), which existed either as stand-alone facilities or as components of acute care hospitals
- Long-term care (LTC) facilities, including nursing homes (largely for-profit) and homes for the aged (not-for-profit)<sup>2</sup>
- To a limited extent, retirement homes (also largely for-profit)

Complex continuing care (previously known as chronic care<sup>3</sup>) hospitals and units currently contain 7,455 beds in Ontario, whereas nursing homes and homes for the aged together account for 58,514 beds (with facilities containing an additional 19,000 beds now in various stages of construction). Historically, admission to these facilities was typically based on the expected hours of nursing care required by the patient. In the mid- to late 1980s, however, rising health care costs forced a reduction in the number of acute care hospital beds, and the number of CCC and LTC<sup>4</sup> beds also shrank in relation to the perceived need. The acuity of illness and complexity of required care increased quickly in all LTC facilities. The differences between LTC and CCC became less distinct, and the justification of funding for the much more expensive CCC hospital beds came into question.

### **Chronic Care Role Study**

The 1993 Chronic Care Role Study (Hay Group 1993) reported the results of an 18-month effort that combined a survey of Ontario's 229 public hospitals with an extensive series of site visits and public consultations. The study produced a set of 42 recommendations to improve CCC service delivery and

to enhance the partnership between CCC and long-term care facilities. The report recommended that CCC hospitals and units target a medically complex patient population and serve as centers of excellence for research and education related to the needs of persons with complex and/or unstable chronic illnesses. The report also identified the paucity of health information on CCC, noting that systems for assessment of needs, classification for funding, and tracking outcomes were inadequate.

Not unexpectedly, the responses of the Ontario Hospital Association (OHA) and the Council of Chronic Hospitals of Ontario expressed both support for and criticism of the various recommendations of the role study (OHA 1993). The most strongly stated disagreements concerned questions such as, Who should be in chronic (complex continuing) care? By how much should the bed capacity for such care in Ontario be reduced? What would be an appropriate funding level for CCC compared with LTC? Regrettably, this debate was essentially bereft of data on which the opponents could base their arguments. While it was easy to obtain consensus on points such as the need to respect the dignity and autonomy of patients, major policy questions related to funding and care needs remained the subject of speculation and argument rather than analysis. According to the OHA response, the role study “consultants’ recommendations suffer[ed] overall from a lack of adequate information to justify their conclusions,” and their recommendations on funding levels were “graphic evidence that the lack of an information system . . . result[ed] in inappropriate decision making” (OHA 1993, 11). Without agreement on the adequacy or veracity of the evidence, agreement on the role study’s conclusions and the “appropriateness” of the recommendations proved hard to reach.

### **Implementation of the Minimum Data Set and Resource Utilization Groups (RUG-III)**

The Ontario Joint Policy and Planning Committee (JPPC) is a partnership of the Ontario Ministry of Health and Long Term Care and the OHA. Although it has played a role in a variety of policy areas, it has been particularly active in refining the basis for funding of hospital-based care. Its committees and working groups typically comprise various stakeholders, including ministry and OHA representatives, hospital executives, clinicians, and researchers.

In 1994 the JPPC established the Chronic Care and Rehabilitation Working Group (CCRWG), which it charged with evaluating available patient classification systems for CCC and with recommending which system should be implemented in Ontario. This work was directly relevant to the recommendation by the Chronic Care Role Study that the “Ministry of Health in collaboration with Ontario hospitals should develop a methodology to determine the necessary funding for the new responsibilities of chronic hospitals and units” (OHA 1993, 23). The aim was to establish a more equitable, needs-based approach to funding CCC, which would replace the existing model of funding individual hospitals based on historical trends.

Although the CCRWG was charged with examining all possible systems, the options it considered rapidly narrowed to existing classification systems that presented at least some evidence of prior and ongoing scientific evaluation. Extensive consideration was given to three systems: the Alberta Resident



Classification System (ARCS; Alberta Health 1988), Resource Utilization Groups (RUG-III; Fries et al. 1994), and the Function Related Groups (FRGs) being developed for the Functional Independence Measure (FIM; Stineman et al. 1994). Among these, ARCS was the initial front-runner. It had been developed in Canada and was already being used to fund long-term care facilities in Ontario. The ministry had put considerable effort into establishing an infrastructure to support ARCS-based funding, and it seemed to make sense for CCC's funding system to be the same as, or at least compatible with, the system used for LTC.

The CCRWG carried out a study in which 812 patients from complex continuing care and rehabilitation hospitals and units were assessed by each facility's nurses using a research instrument that combined the Minimum Data Set, the ARCS assessment used in Ontario, and the FIM. The objective was to determine how the various classification systems would group the same sample of patients. Although FIM data were gathered, the research on FRGs had not been completed to the point that it was possible to evaluate the applicability of that system to the population being studied. The study led to the conclusion that RUG-III, based on MDS data, was the more appropriate classification for CCC hospitals and units because (1) the MDS and RUG-III had undergone more rigorous scientific testing than ARCS; (2) ARCS was insensitive to clinical complexity; (3) MDS had already been implemented nationally in the United States, and there was evidence that its use was expanding internationally; (4) New York State was successfully using RUG-III as a basis for funding nursing homes; and (5) in addition to its use (with RUG-III) as a basis for patient classification, the MDS lent itself to clinical applications that would benefit patients directly (Hirdes et al. 1996; Hirdes 1997). On the recommendation of the JPPC, the Ontario Ministry of Health and Long Term Care made it mandatory for all CCC hospitals and units in the province to assess patients on intake and annually with the full MDS 2.0 and every three months with shorter quarterly MDS assessments. This recommendation also gained support from the Chronic Care Implementation Task Force (1995), which took the position that the JPPC and the ministry should "continue with the development of RUG-III and the Minimum Data Set for use in chronic care hospitals and units" and should "examine the feasibility of coordinating classification systems across sectors of health care."

On July 1, 1996, Ontario became the first province in Canada to implement MDS 2.0 on a province-wide basis. For the first time, CCC could foresee a comprehensive, province-wide health information system that would provide data on clinical characteristics, resource needs, quality, and outcomes of care. Implementation, however, was not smooth. A variety of factors made the introduction of MDS 2.0 in Ontario a substantial challenge:

1. The CCRWG was disbanded prematurely in the belief that further work on its part would not be required.
2. Only one large-scale pilot study of MDS 2.0 had been completed in Ontario (that study was done in Toronto only).
3. There was no pre-existing working relationship with *interRAI*, the international research group that developed and owns the rights to the MDS.

4. Expertise in the clinical, quality, managerial, and policy applications of the MDS and other CCC data was limited to a handful of individuals.
5. The mandate required electronic submission of data, but *interRAI* had not licensed any software vendors to sell MDS software in Canada.
6. The role of the new Canadian Institute for Health Information (CIHI) with respect to MDS 2.0 was undefined, beyond the stipulation that it would train users and act as a repository for the CCC data set.

### **Health Services Restructuring Commission (HSRC)**

At this stage, an entirely new and powerful decision maker entered the scene. In the spring of 1996, the relatively newly elected government of the Province of Ontario introduced legislation<sup>5</sup> that led to creation of the Health Services Restructuring Commission (HSRC), whose fundamental purpose would be to initiate major change in the organization and provision of health care services in Ontario, and to Ontario hospitals in particular.

Canada's other nine provinces had been establishing regional health authorities and gradually making other changes in health care organization and provision. In Ontario, however, four previous governments of different political persuasions had left the status quo relatively undisturbed despite the repeated recommendations for substantial change made over the years by many committees, commissions, task forces, and other groups, as well as the increasingly severe financial constraints placed on health care and other programs, which flowed from the federal and provincial governments' determination to escape and recover from deficit financing of publicly funded programs. (Health care was, and remains, by far the biggest of such programs.)

#### *The HSRC's Role*

The HSRC was to break the logjam, primarily by making major and dramatic changes in the organization of Ontario's public hospitals. Restructuring these highly visible, emotionally laden icons of Medicare would demonstrate to the providers of health care and the general public that change for the better in health care was not just desirable, but possible—and that it was going to happen.

The commission's overarching mandate was to foster progress toward a genuine system of health care services. The legislation passed by the Legislature of Ontario<sup>6</sup> specified a "sunset" for the HSRC in four years (the commission was to function from April 1996 until March 2000) and gave the commission two powers:

- The power to restructure the province's approximately 220 public hospitals, including the power to direct them to close, merge, shift programs, or make any other change the commission considered to be in the public interest. The commission's directions were challenged unsuccessfully in the courts several times over the next four years. They were binding both on the affected hospitals and on the government.

- The power to make recommendations to the government, through the Minister of Health, on how best to restructure other elements of the so-called health services system, including nursing homes, home care, LTC, rehabilitation care, mental health, CCC, primary care, and so on.

Throughout most of its mandate the HSRC was made up of 11 members (including the chair), all volunteers who were each paid one dollar per year. These four women and seven men were a highly diverse group. They hailed from throughout the province—from a small community in the thinly populated north to Toronto, Canada’s largest city. Some were English speakers; others were francophone. They brought to the commission experience gained in a variety of employment backgrounds—both private and public sector—and in a broad spectrum of vocations, which ranged from an owner/operator of a small business to a corporate magnate. Members included a physician, a nurse, an educator/researcher, a lawyer, and a senior public service manager. Some were policymakers; others were implementers of policy. Some were health care providers; others consumers. Their experience in health care encompassed international public health, health professional education and practice, acute and long-term care, institutional management, governance, and philanthropy. No member was charged with representing a particular sector or constituency. Each was expected to bring his or her own perspective to bear on each decision, so that the outcomes would represent as faithfully and objectively as possible the best interests of the public throughout the province.

The HSRC was, above all, an apolitical body. It carefully considered every element in the complex calculus of health care decision making except one. That excluded element was the decision’s political impact, either on the government of the day or over the long term. Despite dire predictions by some politicians and others, the results of the provincial election that was held partway through the HSRC’s mandate appeared completely unaffected by the commission’s decisions. This was true even in areas where those decisions were thought by some to have been contrary to the governing party’s partisan interests. The government was reelected by a substantial majority.

#### *Making Decisions with Sparse Data*

For the first two years of its mandate the HSRC focused on hospital restructuring, beginning with Thunder Bay, a multi-hospital community in northwestern Ontario. It soon became obvious that there were serious deficiencies in the available data—data that were needed as evidence on which to base decisions of many kinds.

Among such decisions were ones related to the capacity of existing health services and requirements for long-term care, including the required number of beds, whether provided in CCC hospitals and units, nursing homes, homes for the aged, or in patients’ own homes (with services provided by home care).

The most comprehensive and reliable data available from the ministry and CIHI related to patients in acute care hospital beds. These data revealed that a substantial percentage of beds in Thunder Bay’s acute care hospitals—and in those of many other communities—were occupied by patients categorized as Alternative Level of Care (ALC), that is, patients who required a less intensive

level of care than that characteristically provided by acute care hospitals. Many such patients had been in acute care beds for extended periods of time. This was so despite the fact that when the commission was established in 1996, there were approximately 9,000 closed (unstaffed) beds (the equivalent of 30 medium-size institutions) scattered throughout Ontario's approximately 220 public hospitals. The cumulative budgetary constraints noted above had led to the closing of these beds and corresponding staffing reductions, yet no hospital had closed.

In exploring options to make the organization of Ontario's hospitals more rational, it was essential to consider two issues: (1) how and where to consolidate acute care services to create more efficient and effective physical plants; to decrease administrative, managerial, and maintenance costs; and to provide an environment supporting higher quality of care; and (2) where patients categorized as ALC should best be cared for. It soon became apparent that the Alternative Level of Care category was a catchall designation; it merely identified patients who did not need the services of an acute care hospital. Without finer gradation, it was impossible to make definitive judgments on the proportion of patients in need of CCC, those needing the services of an LTC facility, and those who could be cared for safely and well in their own homes with support by home care. In the words of the commission, "In general, there are no evidence-based guidelines nor an evaluative framework available to determine the appropriateness (or adequacy) of chronic care bed supply or other long term care services" (HSRC 1998).

This deficiency was as applicable to CCC hospitals and units as to LTC facilities and home care. Data from the province-wide implementation of MDS 2.0 in CCC facilities were not readily available in 1997, when the HSRC's *Interim Planning Guidelines and Implementation Strategies* document was released. As a result of the challenges encountered during the first year of implementation, a full year's worth of MDS 2.0 data was not available until late in 1997. By default, the primary CCC data source available to the commission was a 1995 study by the Metropolitan Toronto District Health Council in which about 1,200 patients in 13 Toronto chronic care hospitals and units were assessed using the MDS. Other smaller MDS data sets were available from Thunder Bay and Niagara, but the Toronto data were the most comprehensive.

The following year, the commission released a report (HSRC 1998) that distinguished between LTC beds and CCC beds based, at least in part, on RUG-III categories, with patients in the Clinically Complex, Extensive Services, and Special Care levels generally designated for CCC and those in the Behaviour Problems, Impaired Cognition, and Physical Functions Reduced categories designated for LTC. The commission did not direct that patients falling into the latter categories were to be relocated. Rather, these categorizations were to be used as guidelines in planning new admissions to CCC hospitals and units.

In a report to the Ministry of Health and Long Term Care, Hirdes and colleagues (2001) noted that 68.1 percent of LTC residents, as compared with 21.4 percent of CCC patients, fell into the lowest three RUG-III hierarchy levels, which was consistent with HSRC directives about the relative roles of these types of facilities. When new admissions to CCC were compared with existing CCC patients

(Teare et al. 2000), the shift toward more short-stay, clinically complex patients in CCC became even more pronounced. Hence, although data were not readily available at the time the commission made its decisions about the proportion of patients requiring CCC, it later became possible to monitor the extent to which its directive that these patients be admitted to the hospital and all others be admitted to institutional or home-based care was translated into practice.

#### *Recommendations for Assessment and Classification Systems*

Ontario's health care system has become increasingly complex over time. Some of the growth in complexity is the result of fragmentation: in addition to nursing homes, homes for the aged, and chronic hospitals and units, organizations providing services to the frail elderly and people with disabilities include psychiatric hospitals and units, rehabilitation hospitals and units, acute care hospitals, retirement homes, assisted living complexes, and Community Care Access Centres (CCACs).<sup>7</sup> One central difficulty posed by this multiplicity of providers is that these organizations have historically used different, incompatible assessment and classification systems. This has had the effect of restricting policymakers' ability to evaluate data—when data are available at all—from a system-wide perspective. These different providers' inability to communicate has an effect on patients, as well, reducing continuity of care as individuals move from one type of provider to another. And from the health care provider's perspective, the lack of common classification systems, at least between LTC and CCC, has perpetuated perceptions of inequities in funding. The level of funding remains more a function of the type of facility in which a specific patient resides than of what his or her actual needs (and the associated costs of service provision) are. For this reason, the commission recommended that

The Ministry of Health [should] work with CCACs across the province to develop an accountability framework that will support effective implementation of home care reinvestment in the province. The accountability framework should be supported by the early development of an information system that will introduce more consistent standards for data collection and analysis, and allow comparison of data across home care programs and with hospitals. (HSRC 1998, 18)

The Ministry of Health, in collaboration with chronic hospitals/units, physicians, nursing homes, homes for the aged, supportive housing services and CCACs, should expedite the development of a single point of access and adoption of a unified classification system for determining eligibility and placement into LTC facilities (including CCC beds). Because of the importance of the tool in ensuring appropriate placement in and access to LTC services, the HSRC recommends adoption of the Minimum Data Set (MDS) tool. (HSRC 1998, 45)

At the end of its mandate, the commission released a summary report (HSRC 2000) that continued to stress the need for common classification systems for LTC and CCC based on the MDS.

Although in some ways progress toward the goal of a comprehensive health information system (Sinclair and Hooper 1998) has been slower than hoped, Ontario's CCC has made some important

positive steps that have been extended to other kinds of care settings. First, the JPPC Psychiatric Working Group and interRAI have spearheaded an effort to create an assessment system for inpatient psychiatry that is compatible with MDS 2.0 while at the same time measuring the particular needs of psychiatric patients (see Hirdes, Marhaba, et al. 2001 for details). Second, the CCACs and the Ministry of Health and Long Term Care have worked together to conduct a review of available assessment systems for home care. The ministry has recently identified MDS–Home Care (Morris et al. 1997, 1999) as the provincial standard for the assessment of patients receiving community-based care. Third, a large-scale project funded by Health Canada’s Health Transition Fund allowed for a six-city trial that piloted MDS instruments for long-term care, home care, mental health, and acute care with the goal of refining the use of interRAI’s series of instruments to serve as an integrated health information system (see Hirdes, Fries, et al. 1999). One product of this study was the aforementioned report (Hirdes, Fries, et al. 2001), which, for the first time, allowed for a direct comparison, based on MDS 2.0, of needs, access to services, resource intensity, and clinical characteristics of persons in LTC facilities and CCC hospitals and units in Ontario.

#### **THE DAWN OF THE INFORMATION AGE**

Five years after the Ministry of Health and Long Term Care made MDS 2.0 mandatory for CCC hospitals and units, the time has clearly passed when policymakers, managers, and service providers had to make decisions in the absence of evidence. CCC has made notable steps forward in two areas: case mix–based funding and quality reporting systems.

#### **A Case Mix–Based Funding System**

In April 1998, the Ontario Ministry of Health and Long Term Care approved the JPPC Hospital Funding Committee’s recommendation that RUG-III be used as the basis for funding CCC. The JPPC established the Complex Continuing Care Funding Working Group to develop operational recommendations for the funding methodology Ontario should use to translate RUG-III scores and other information into a payment system for CCC (JPPC 1999). Technical issues the working group addressed included conversion of RUG-III Case Mix Index weights from U.S. values to weights, based on Ontario wage rates, derivation of RUG-III-weighted patient days to account for the resource intensity of patients over the duration of their stay in a given year, establishment of data quality checks to ensure complete capture of the volume of patient activity, and specification of various alternatives for the funding formula (Teare 1999).

The first application of RUG-III-based funding for CCC occurred in the spring and summer of 2001, when RUG-III was used as part of a formula to allocate funding based on relative efficiency in the use of CCC beds. This formula is now integrated into an ongoing framework for CCC funding. In addition, RUG-III results were used to specify new allocations of beds for CCC in November 2000, and

the ministry now requires CCC hospitals and units to report on the acuity and resource intensity of their beds using MDS data.

Despite considerable progress in the implementation of a RUG-III-based funding methodology, some operational complexities remain. In particular, the use of RUG-III for CCC units within acute hospitals and Case-Mix Groups™ (CMGs™)<sup>8</sup> for acute care beds means that those facilities must contend with two distinct funding approaches: a per diem system for CCC beds and an episodic system for acute care beds. This is not to say that this issue would not have been of concern had another system been put in place for CCC. ARCS, which the JPPC deemed inadequate for CCC, is also a per diem system; its application would have resulted in the same problem in acute care hospitals. Similarly, CMGs cannot be applied to CCC; episodic models are ineffective when applied to populations of long-stay patients because of the substantial variability in length of stay and in resource utilization over the course of the episode (JPPC 1999).

### **Quality Initiatives Based on MDS 2.0**

One of the primary applications of MDS data is in evaluating the processes and outcomes of care with a series of quality indicators developed by Zimmerman and colleagues (1995). The Chronic Care Role Study called on the Ministry of Health to “develop appropriate outcome measurements for quality of life, quality of care, and methods of client empowerment.” Five years after MDS 2.0 became mandatory, CCC now has an active provincial quality network, annual reports on the status of CCC prepared by CIHI, and the capacity to use those data as part of a province-wide public report card initiative.

#### *Ontario MDS Quality Network*

As mentioned, the initial implementation of MDS 2.0 was a relatively challenging process complicated by a lack of experience at many levels, short time frames, and ambiguity regarding the roles of various stakeholders. The first meeting of the Ontario MDS Quality Network was held in Toronto as a result of the combined leadership of three hospitals: Sunnybrook Health Sciences Centre, Providence Centre, and SCO Elizabeth Bruyère. Until this point, the potential of MDS data to affect quality of care was not well known in Ontario, but after a relatively short period of time it became clear that their utility in quality improvement would become one of the main factors to increase the sustainability of MDS 2.0 in CCC.

One of the most visible quality issues had to do with the use of physical restraints. This issue gained the attention of members of the Ontario MDS Quality Network in part because the Providence Centre’s 1997 Accreditation Survey had cited restraint use as an issue of concern. When data from this and other Toronto facilities were compared with international data available through *interRAI*, the rates of restraint use in Ontario were found to be substantially higher than in other jurisdictions (Hirdes, Mitchell, et al. 1999). These results stimulated considerable debate in the provincial quality network over what constitutes a restraint and what standards should apply to CCC patients in Ontario.

Interest in the issue grew within the health care system and in the media when reports commissioned by CIHI demonstrated substantial regional variability in the use of restraints. In the summer of 2001, Frances Lankin, a former Minister of Health from a previous government, put forth a private member's bill on restraint use that passed in the provincial legislature. This bill's intention to improve practice patterns related to the use of restraints cannot be attributed solely to the effects of implementing MDS 2.0 in Ontario CCC, but the debate on restraint use was clearly enhanced by the availability of credible evidence. The effect of the bill will be easy to evaluate given that directly relevant data will be available to all interested parties.

#### *CIHI Provincial Status Reports*

Beginning in 1998, CIHI commissioned a series of annual reports on the quality of care in Ontario CCC hospitals and units. Nenadovic and colleagues (1999) provided the most extensive report up to that point on applications of MDS 2.0 for case mix, quality, outcome measurement, and care planning. The report included regional comparisons of Zimmerman and colleagues' (1995) quality indicators and demonstrated clear practice pattern differences among the five main OHA regions. It also brought the restraint issue to the public's attention for the first time by demonstrating that about one-third of CCC patients were being restrained. The following year (2000), the CIHI report included temporal analyses of trends in quality indicators and a special report on restraint use (Teare et al. 2000). This was also the first year that CIHI provided hospitals with personalized reports detailing their own performance on these quality measures compared with other CCC facilities. CIHI intends to continue releasing these types of in-depth reports coupled with hospital-specific results on an annual basis.

#### *OHA Report Card*

In 1999, the OHA publicly released its first balanced scorecard for acute care hospitals. The scorecard rates individual hospitals against four main sets of indicators: clinical and utilization, financial, patient satisfaction, and system integration and change. In 2001, the OHA released its prototype balanced scorecard for CCC, making heavy use of MDS 2.0 data for the financial and clinical indicator quadrants. The initial CCC report card dealt only with regional differences, but in subsequent years it will be expanded to include hospital-specific results. It should be noted, however, that the quality indicators in the report card relate only to long-stay patients because the current MDS 2.0 implementation does not include discharge assessments for persons discharged before their regularly scheduled 90-day reassessment. The report card's section on system integration and change includes an examination of the extent to which MDS applications for care planning, outcome measurement, quality improvement, and resource allocation have been incorporated into a facility's normal practice.

## **LESSONS LEARNED**

Although it is difficult to summarize more than a decade's worth of changes in health policy related to



CCC, it is possible to point to some major lessons learned from Ontario's experience. These lessons include the following:

1. *Evidence is an essential ingredient for change.* The debate following the Chronic Care Role Study showed that the absence of evidence hindered agreement on the place of CCC in the continuum of care. Although the HSRC used what evidence was available as the basis for its basic decisions about CCC in relation to LTC, the commission might have been much more innovative had it had the type of data now available for CCC.
2. *It takes effort to get good data.* It is not enough that all providers of health care are gathering data. Standardized, valid, reliable data are the necessary, fundamental building blocks to evidence-based decision making in health care. Acquiring such data requires systematic implementation of a common assessment methodology with appropriately trained staff, effective quality monitoring systems for data, and high levels of analytic expertise. For health care to truly come into the Information Age, health information management must have the capacity to embrace all the "players." Developing this capacity will not happen overnight, nor will it occur without substantial investment of resources and a collaborative effort on the part of governments and providers throughout the system.
3. *Beware the black hole.* The single most important threat to the successful implementation of MDS 2.0 in Ontario was the absence of feedback in the form of reports to providers of the data. Even after many years of data collection, most Ontario hospitals with CCC beds had received only limited hospital-specific results based on their MDS data. Staff and administrators' efforts to gather data went unrewarded by information until the establishment of the Ontario MDS Quality Network and the release of CIHI's first mini-status report in 1998.
4. *Ongoing training and education are essential at all levels in health care.* Effective implementation of a health information system is a complex undertaking requiring the full participation of many stakeholders. It cannot be assumed that individuals with professional training as clinicians, managers, or policymakers know how to incorporate evidence-based decision making into their daily work. Particular emphasis should be given to incentives so that those contributing data will make full use of the information in applications relevant to them. Without such incentives there is considerable risk that information systems and the evidence they generate may suffer from reduced accuracy or incompleteness. Training that emphasizes benefits to the individual and organization and that enhances autonomy in decision making will be more effective than mechanistic training approaches in ensuring uptake.
5. *Sometimes change must be mandated.* Ontario made MDS 2.0 mandatory for chronic hospitals and units after a two-year consultation and study process. At about the same time, Saskatchewan opted for the "slow seduction" approach by implementing MDS 2.0 in one Health Region (Prince Albert) and waiting for others to follow suit. After several years, implementation remained partial, and Saskatchewan ultimately mandated the submission of RUG-III data in April 2001. Despite the period of considerable difficulty that Ontario

endured as it initially struggled to implement MDS 2.0, the province now has five years' worth of useful data to evaluate policy changes and plan for future directions in CCC.

6. *Sometimes it is necessary to fracture the status quo.* Although Ontario's Health Services Restructuring Commission put fewer reforms in place than its members would have preferred, it remains true that this body, legislatively empowered to direct change, created an environment in which change could occur by fracturing the status quo. Most of the commission's directions and recommendations would not, perhaps could not, have been made had the usual, time-consuming processes of consensus-building and balancing diverse and divergent interest groups not been short-circuited by the HSRC's mandate and powers.
7. *Weak data are the Achilles' heel of a policy debate.* Some CCC hospitals slated to close by the HSRC remain open today because they were able to use political pressure to question the HSRC's per capita guidelines for CCC bed allocations.
8. *Involving a broad range of stakeholders in decision making is an important condition for successful change.* The JPPC's CCRWG included active participation by hospital administrators, clinicians, policymakers, and researchers. This gave the committee the ability to address key questions on the information needs of CCC from a variety of perspectives. It also provided a nucleus of opinion leaders who could represent and speak to different influential constituencies (e.g., geriatricians) within CCC.

#### **PROSPECTS FOR THE FUTURE**

In an August 1993 letter to the minister of health, the president of the Ontario Hospital Association wrote, "We cannot move the chronic and long-term care system forward without a solid base of information on which all interested and involved parties can make informed planning and management decisions." Without doubt, CCC in Ontario has made substantial steps forward since that time. Nonetheless, there remain many key challenges that must be addressed if the new system is to be sustained and enhanced.

No fundamental change in LTC health information systems has occurred since the HSRC first made its observations about the lack of evidence for bed allocations in 1997. LTC facilities continue to use a system (ARCS) that is incompatible with the MDS 2.0 system implemented in CCC. An important constraint for the industry and the government has been the cost of implementing an adequate computerized infrastructure to permit the effective use of instruments like MDS 2.0 in LTC facilities. Meanwhile, LTC faces increasing numbers of residents with higher levels of clinical complexity, and the insensitivity of ARCS to this complexity will make it difficult to allocate resources in a way that is truly responsive to the needs of individuals in nursing homes and homes for the aged. Until these two sectors share a common assessment and classification system with CCC, it will be impossible to make direct comparisons of the costs, quality, and relative outcomes of these different forms of long-term care. In 2000, an advisory committee to the Ministry of Health and Long Term Care conducted a

review of assessment and classification systems for LTC. The committee concluded that LTC had no practical alternatives to MDS 2.0, and it was supportive of a pilot project to test the feasibility of using MDS 2.0 in LTC (Ministry of Health and Long Term Care 2000). Funds for such a project were not available at the time, however, so the effort had to be temporarily delayed.

The quality of data appears to have been reasonably good for the first five years of MDS 2.0 implementation in CCC. The primary concern noted by the JPPC in preparing for RUG-III-based funding models has been in regard to the *completeness* of MDS data sent to CIHI rather than the accuracy of the clinical information (e.g., patient days in the MDS records did not account for all patient days in the facility census). As CCC begins to implement RUG-III-based funding, the gaming of assessment systems for financial purposes may emerge as a threat to data quality. Based on U.S. experience, one may expect unscrupulous software vendors or consultants to develop and market products aimed at maximizing mean case-mix index scores rather than maximizing the accuracy of observations. Controlling this will require a multifaceted approach, including training administrators in the pitfalls (and ethics) of gaming, establishing audit systems to monitor data quality, and using quality benchmarks to track quality of care. The JPPC has established a CCC Technical Working Group to review the potential for gaming and to establish mechanisms to control the problem.

Clinicians, managers, and policymakers have underutilized the wealth of data now available to CCC. A number of factors may account for this. Ontario clinicians have had relatively little training in the use of MDS data for care planning or for measuring outcomes. This has been less of a concern in provinces (e.g., Manitoba, Nova Scotia, British Columbia) where current pilot implementations have placed much greater emphasis on clinical applications than on funding systems. At the ministry level, two divisions (Health Care Programs and Integrated Policy and Planning) are working to improve internal processes to organize and analyze MDS 2.0 data.

A lack of expertise and the relatively high level of technical complexity associated with quality and funding applications of MDS 2.0 data may be a barrier for some managers and policymakers. This is not necessarily unique to the MDS assessment system, since evidence-based decision making is inherently complex. As Sackett and colleagues (1997) note, an evidence-based health system will demand of its participants a commitment to lifelong learning together with the capacity to integrate new knowledge with their professional experience. The challenge is at least twofold: educating professionals in how to incorporate evidence-based decision making into their work lives and training them in the substantive knowledge required to make full use of all MDS applications. This can only be achieved by making clear how all of the effort of implementing such a system can benefit health professionals and the populations they serve.

## GLOSSARY

ALC .....	Alternate Level of Care
ARCS .....	Alberta Resident Classification System

CCAC	Community Care Access Centre
CCC	Complex Continuing Care
CCRWG	Chronic Care and Rehabilitation Working Group
CIHI	Canadian Institute for Health Information
CMGs	Case Mix Groups
EBDM	Evidence-based Decision Making
FIM	Functional Independence Measure
FRGs	Function Related Groups
HSRC	Health Services Restructuring Commission
JPPC	Joint Policy and Planning Committee
LTC	Long-Term Care
MDS	Minimum Data Set
OHA	Ontario Hospital Association
RUG-III	Resource Utilization Groups

#### NOTES

- 1 Complex Continuing Care hospitals have patient populations that are similar to those of skilled nursing facilities and chronic care hospitals in the United States. These patients tend to be more severely functionally impaired than residents in long-term care facilities in Ontario, and their problems are more clinically complex.
- 2 In the past, LTC facilities were funded separately because of their different relationships with two provincial ministries (initially the Ministry of Health for nursing homes and Ministry of Community and Social Services for homes for the aged), even though they were accommodating residents with similar care requirements. Reform of the LTC system brought all facilities together under one administrative, funding, and accountability structure under the Ministry of Health and Long Term Care.
- 3 The term *Complex Continuing Care hospitals* was introduced to replace *chronic care hospitals* by the Health Services Restructuring Commission in its July 1997 report, *Rebuilding Ontario's Health System: Interim Planning Guidelines and Implementation Strategies*.
- 4 Throughout this case study, the term *long-term care facility* will be used generically to refer to both nursing homes and homes for the aged in Ontario.
- 5 The Savings and Restructuring Act, 1996 (S.O.1996, Chapter 1, Schedule F ["Bill 26"]), which repealed section 8 of the Ministry of Health Act and substituted a new section 8.
- 6 The regulations mandated by the Ministry of Health Act (O.Reg.88/96) and the Public Hospitals Act (O.Reg.87/96) came into force on April 1, 1996. The powers given to the commission in these two statutes, together with the provisions in section 8 of the Ministry of Health Act and sections 6 and 9(10) of the Public Hospitals Act constituted the powers and authority of the commission.

- 7 CCACs are single-point-entry agencies that act as contracting agents with home care providers for the populations they serve. They make all decisions about the level and number of hours of home care services the client will receive, as well as all decisions about admission to LTC and, if requested by the facility, to some CCC hospitals and units.
- 8 CMCs™ are the Canadian equivalents of the Diagnosis Related Groups used in the United States.

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**TOWARD INFORMED AND EVIDENCE-BASED ELDERLY CARE:  
THE RAI EXPERIENCE IN ICELAND**  
Pálmi V. Jónsson and Hrafn Pálsson

**EXECUTIVE SUMMARY**

Iceland may be viewed as a microcosm of Western societies, and lessons learned in Iceland may be applicable in larger countries. Until 20 years ago, the development of elderly care in Iceland was haphazard. In 1982 Iceland passed laws dealing specifically with issues relating to the elderly. The laws mandated that a Nursing Home Preadmission Assessment (NHPA) be performed on anyone applying for nursing home placement to confirm and grade the need for long-term care. Though “homemade,” this system opened the eyes of policymakers to the value of objective assessment and data gathering, and the NHPA had definite consequences on the further development of nursing home care in Iceland.

The content and quality of nursing home care in Iceland were almost completely unknown in the early 1990s. Costs were considerable, and the financing of nursing home care was variable. This began to change when two Icelandic geriatric professionals brought information on the RAI system to Iceland and began discussing its potential use in the country’s nursing homes. The permanent staff of Iceland’s Ministry of Health soon secured political support for exploring the utility of the RAI system in elderly care. The ministry established a national *IceRAI* steering committee with key players from health and social services.

The RAI system, which assesses individuals, cut through the maze of health care systems and provided important—and hitherto unimaginable—insights about the quality of care in Iceland compared with that in other countries. Nursing home staff were systematically trained in the use of the instrument and supported through the assessment process.

Based on its experience with a pilot study, the Ministry of Health decided to mandate the use of the RAI system in all of Iceland’s nursing homes. Overall, the RAI system was favorably received, although some voiced concern about the amount of time the assessment required.

Implementation of the RAI has had several spinoff effects. For example, because the method of financing care (whether through a fixed budget or on a per diem basis) has not necessarily mirrored a particular nursing home’s case mix, it has been decided that all nursing home care will now be based on the RAI resource utilization groups (RUGs). Other spinoff effects include the monitoring of quality of care and the generation of clinical guidelines for identified problem areas. The database accumulated through use of the RAI will be the first to appear on Iceland’s new Universal Health Care Intranet. Some components of the RAI system are still underutilized in Iceland, which shows that systemic change is a long-term development, not a sudden revolution.

The perceived benefits of the RAI system in the nursing home arena are certainly viewed as an encouraging model for other parts of the elderly care system. The *IceRAI* steering group has continued to study the value of other RAI-based assessments. It conducted a pilot study of home care in 1997, and during 2001–2 was engaging in a second pilot as a part of a broader European study. Interest in an RAI home care information system is growing, although it is too early to tell whether this system will be used as extensively as the nursing home system has been. RAI-based systems for

acute care and mental health care are now being studied, as well. All this activity raises the possibility of a seamless system of assessment and care of the elderly. It is an appealing concept in Iceland.

The timing of the RAI's introduction in Iceland was optimal. The RAI system of elderly care came to the attention of policymakers at a moment when their interest in objective evaluation was growing. At the same time, professional knowledge of geriatric medicine and nursing was increasing. The RAI's implementation in Iceland has been a mixture of "top-down" and "bottom-up" approaches—a process in which policymakers, researchers, and caregivers have converged in the middle.

## **ON ICELAND**

Iceland is a geographically large country (43,000 square miles) with a small population. Iceland's population now numbers about 230,000; about 11 percent of Iceland's people are 65 or over, and about 25 percent are under the age of 15. In 1992, life expectancy at birth was 76.9 years for men and 80.8 years for women. The infant mortality rate was 5.5 per 1,000 live births, which, along with Japan's and Sweden's, ranks among the lowest in the world. Despite Iceland's small population, its low infant mortality and high life expectancy make it a kind of microcosm of the developed world, and lessons from Iceland may therefore be applicable to larger societies, especially in Europe.

Iceland's population grew rapidly during the 20th century, from only 78,000 in 1901. Social development has likewise been tremendous, with the country moving from being an underdeveloped, predominantly agricultural nation at the time of World War II to a highly developed, information-based society at the beginning of the 21st century. During this period of transformation, Iceland has gone through the "classic" changes in family structure—from large, multigenerational families that took care of their own elderly to small, nuclear families in which women work outside the home (Jónsson 1998).

More than half of Iceland's inhabitants live in or around Reykjavik, the capital. The first nursing home in Reykjavik was built in the 1930s; the second was constructed in the 1950s. These first nursing homes had mixed levels of care, with both skilled and unskilled nursing. Most of the skilled nursing homes in Iceland have been built since 1980, and it has only been during the last 10 to 15 years that serious attempts have been made to understand the care needs of the elderly and to respond to those needs in an informed way. Nursing home demand has not yet been met, and that demand will grow: by 2030, the elderly (those 67 and older) will represent 16.5 percent of Iceland's population, with the proportion of the "oldest old" growing most rapidly.

In the year 2000, the Icelandic government spent 7.7 percent of its gross domestic product on health care, including long-term care. (Without long-term care, health care costs amount to about 7 percent of GDP.) Iceland's health care system is nationalized, though there are private-sector entities on the provider side. On the purchaser side of the system, two actors fund health care services: (1) the National Institute of Social Security, which is financed through the central government's budget and through employers' and employees' contributions; and (2) the central government's annual

appropriation, financed through general taxation, which directly allocates financial resources to hospitals and primary care services. The rich and the poor use the same system, contributing copayments of 25 to 30 percent of the cost (with a limit on maximum expenditure). However, the copayments of the elderly amount only to one-third of what actively working citizens pay, and no copayments are required for hospitalization or rehabilitation. Nursing home placement costs the elderly up to US\$1,000 per month (if their pensions are generous enough), and Iceland's national health insurance pays the balance of about US\$2,000 per month and also covers whatever portion of the cost that a resident's pension does not. The elderly do not have to spend down other assets to pay for their care (Jónsson 1999).

#### **NURSING HOME PREADMISSION ASSESSMENT**

Iceland first enacted laws dealing specifically with issues relating to the elderly in 1982, revising the laws in 1989 and again in 1999. The laws' underlying principle is that the autonomy of the elderly shall be respected. The elderly have a legal entitlement to required services, and the state must meet their needs in a way that is relevant and economically feasible. The elderly must be supported in their homes for as long as possible and have access to a nursing home when the need arises. The Ministry of Health is responsible for the care of the elderly; the management of such care is in the hands of a division chief and the five-person Council on Elderly Affairs. A tax of about US\$40 per person per year facilitates the development of care for the elderly.

Care of the elderly has two components: health care and social services. Health care is organized regionally, through primary health care centers, and is paid for by the state, funded through the central government's budget. Social services are also organized regionally (albeit in a different way from health care), and are paid for by county councils, which are funded by local governments. Social services include assistance with home care and daycare. Geriatric hospital care, which has developed rapidly during the last 20 years, is financed by the state.

Icelandic law mandates use of the Nursing Home Preadmission Assessment (NHPA; Jóhannesdóttir and Jónsson 1994); no one can enter a nursing home without undergoing this certified need assessment. A multidisciplinary team performs the NHPA; the team consists of a physician, a nurse, a social worker, a representative of the municipality, and a representative of the Association of Elderly Citizens (this last team member participates only in planning decisions, not in the clinical assessment). The assessment is standard in form and content. It remains valid for up to 18 months, though it is supposed to be revised if the applicant's condition or situation changes during this time. The NHPA system generates national and regional waiting lists for the 3,700 beds currently available.

Nationwide, 13 percent of Iceland's elderly reside in nursing homes, though the figure is lower (9.7 percent) in Reykjavik (Ribbe et al. 1997). About 80 percent of the people in Iceland's skilled nursing homes and about 40 percent of those in unskilled nursing homes suffer from dementia of

some kind and degree of severity. (Unskilled facilities in Iceland are similar to residential care facilities in the United States.)

#### **PROBLEMS IN ELDERLY CARE**

Iceland's responses to the need for elderly care have been both empirical and somewhat chaotic. The philosophy of elderly care is in many ways clear, but the system lacks comprehensive administration and is therefore fragmented (as is the health care system in general). The system's major drawbacks are these:

1. Health care and social services within communities are not coordinated, in part because they are funded by different sources.
2. Nursing homes have autonomy regarding the admission of new residents and are not officially obliged to first accept those on the waiting list who are in greatest need or those in hospitals who are waiting for nursing home beds. In areas where the need for nursing home beds exceeds the supply, some nursing homes engage in "cream skimming," admitting applicants still living in the community before those in greater need who are waiting in hospitals.
3. Because of limited availability, primary health and home care services are insufficient to adequately care for elderly people living at home. This factor, combined with nursing homes' selection process, leads to the "bed blocking" of elderly in hospitals—an inefficient use of resources.
4. Funding of nursing home care has been inconsistent: some nursing homes are reimbursed based on a fixed budget and therefore have no incentive to keep their beds fully occupied at all times; others are paid on a per diem basis, but the reimbursement rates vary widely.
5. The quality of care received by Iceland's elderly has largely been an unknown.

#### **INTRODUCTION OF THE RAI IN ICELAND**

It is against this background—a rather chaotic system of elderly care but also a climate in which policymakers were increasingly interested in creating policies that would truly be responsive to the needs of the elderly—that the Resident Assessment Instrument (RAI) entered the picture in the early 1990s. By chance, two professionals who together were subsequently to lead geriatric medicine and nursing at one of the two Reykjavik hospitals were introduced to the RAI system. These were Pálmi V. Jónsson and Anna Birna Jensdóttir.

The interRAI group invited Jónsson to join it in November 1991, two years after he had returned to Iceland from the United States. Jónsson had been a fellow in geriatric medicine at Harvard Medical School in the late 1980s, during the time when the early development of the Minimum Data Set for Nursing Homes (MDS-NH) was taking place. In fact, he had worked with Lewis A. Lipsitz and John N. Morris on the resident assessment protocol dealing with the problem of falls among the elderly of that earliest version. The RAI for Nursing Homes (RAI-NH) was an entirely American development, but

shortly after its introduction in the United States an international group formed to study the RAI's application in other countries (Hawes et al. 1997; Morris et al. 1990). Work on further development of an applied assessment system for the elderly began in various settings.

Also in 1991, Anna Birna Jensdóttir, the head geriatric nurse at what was then Reykjavik City Hospital, was introduced to the system in Denmark by Marianne Schroll and her coworkers. Though Jónsson and Jensdóttir worked in the same department of geriatrics, they independently arrived at the conclusion that the RAI could have great value for the system of elderly care in Iceland, and Jónsson introduced it to Hrafn Pálsson, chief of elderly affairs for the Ministry of Health.

Pálsson, too, appreciated the RAI's potential value. Recent experience with the NHPA had demonstrated that policy- and decision making might be transformed by the use of objective, standardly defined data. There would no longer be any need to argue about what the facts were; the standardized measurements would reveal the facts, and discussion could shift toward solving the problems disclosed by the measurement tool.

The then Minister of Health, Sighvatur Björgvinsson, secured minimal funding from the Council on Elderly Affairs and in August 1993 formed the specially appointed *IceRAI* committee. At the beginning, it was headed by Jón Karlsson, a political adviser to the minister; the other members included Jónsson, who served as project leader; Jensdóttir (secretary); Pálsson; Sigurbjörg Sigurgeirsdóttir, the Reykjavik municipal government's chief of elderly affairs and services to the elderly; and two geriatric nurses, Ingibjörg Hjaltadóttir and Hlíf Gu\_mundsdóttir, who directed daily operations.

Because the RAI was a foreign system, unknown in Iceland at the time, it could well have been met with skepticism. After all, health and social welfare systems are heterogeneous and difficult to transplant from one nation to another. It was therefore crucial to obtain political support for exploring the possibility of introducing the RAI system in Iceland. With a change of ministers, Jón Karlsson left the Ministry of Health, and Hrafn Pálsson took over as chairman of the *IceRAI* group. *IceRAI* thus became part of the overall operation of the Ministry of Health and Social Security, and all subsequent ministers—Gu\_munder Árni Stefánsson, Ingibjörg Pálmadóttir, and Jón Kristjánsson—have supported the RAI work. Each has had the benefit of the increasing accumulation of evidence favoring the RAI, as the instrument's use has incrementally spread and developed over the past decade. Trust and free-flowing communication among key players in the health and social services system, coupled with political support, got the RAI initiative off the ground. And the geriatric nurses' strong leadership met with a positive response on the grassroots level, because those in the nursing profession were increasingly aspiring to do academically sound, high-quality work.

From the beginning, the *IceRAI* committee has met regularly to develop and support the RAI agenda. It launched a pilot study of nursing home care and later promoted a study of home care; studies of mental health care and acute care are currently ongoing. Throughout its existence, the *IceRAI* committee has promoted the regular use of RAI in the nursing home setting, as outlined below.

The formation of a national Icelandic steering committee has been crucial in promoting and maintaining enthusiasm and support for the RAI-NH system in Iceland. *IceRAI* is linked to *interRAI*

by Pálmi V. Jónsson, who is an *interRAI* fellow. The contact with *interRAI* has sustained the flow of ideas and new developments to Iceland. No less important, Nordic cooperation has flourished, with all five Nordic nations forming a special alliance called NordRAI. In 2000, the Nordic Council of Ministers decided to support the work for five years to come. The Nordic cooperation has been particularly important with regard to the implementation and computerization of the instrument and the training in its use in each of the Nordic countries. The Nordic countries are quite homogeneous in population, and their health and social care systems are very similar, although there are differences on which the RAI will shed light. This is a great achievement that looks back to the first pilot study.

In 1994, the *IceRAI* group decided to carry out a pilot study of the MDS-NH 1.0 instrument in three areas of Iceland: the greater Reykjavik area; Akureyri, the largest city in northern Iceland; and Kirkjubæjarklaustur, a small community in the southern countryside of Iceland. Reykjavik City Hospital's ethics committee and the Icelandic Data Protection Committee approved the study, and the *IceRAI* group sought patients' informed consent. Ultimately, the study included 1,641 participants—91 percent of those who had been approached in 15 nursing homes and 64 care units. Only 1.3 percent actually declined to participate; the remaining 7.7 percent either died before they could participate or were prevented from participating because of a local strike by nurse's assistants.

The pilot was the first objective study of nursing home residents in Iceland. Two-thirds of the participants were women. The average length of stay was relatively long: slightly over three and a half years. About half of all nursing home residents in Iceland have dementia of some sort, but that figure rises to 80 percent in the skilled nursing home sector. Of the latter group, only 15 percent were judged by the staff according to the MDS-NH assessment to be capable of independent decision making. Only 5 percent of the medical and nurses' records indicated legal restrictions on residents' decision-making capacity according to the same assessment. The high percentage of those who are actually incapable of independent decision making carries an important lesson: the elderly are at risk for financial abuse. Indeed, the number of cases of financial abuse of the elderly has risen markedly in recent years, and it is clear that methods for protecting the elderly financially must be put in place.

A quarter of the residents participating in the study had serious hearing impairments, and more than one-third had serious vision problems. More than 80 percent wore dentures. Although most of the residents could make themselves understood, functional impairment in the activities of daily living (ADL) was prevalent in skilled nursing homes, as expected. One-fifth of residents expressed feelings of depression. Only 40 percent were able to watch TV or listen to radio. Pain was a common complaint, and, on average, residents were taking seven medications, including vitamins. One-fourth of the residents were receiving antidepressants, and 60 percent regularly took hypnotic medication. The data about the prevalence of the use of medications—particularly psychotropic medications—in Iceland's nursing homes raised some eyebrows, especially as it became clear that Iceland's nursing homes were using the psychotropic medications at double the rate of nursing homes in two other Nordic countries, Sweden and Denmark (Jónsson et al. 1997).

## FOLLOW-UP STUDIES

The pilot prompted two small follow-up studies. One further explored the use of psychotropic drugs. The study, whose results were published in the Icelandic medical journal, *Læknablaðið*, concluded that the treatment of depression in Iceland's nursing homes, while not perfect, is probably better than in other Nordic countries (Kjartansson and Jónsson 1999). Commonly, depression is underdiagnosed and undertreated in the nursing home setting. The inappropriate use of antipsychotics was uncommon: generally, the doses administered were low, and residents receiving antipsychotics were monitored for progress and side effects. What stood out, however, was an unjustifiably high use of hypnotic medications. The result of this study fueled an intervention study in which nursing home residents were gradually weaned off the hypnotic medications by being given decreasing dosages as well as educational support. Three months after the intervention study's conclusion, half of those who had been weaned from hypnotics remained off the drugs and were sleeping longer and reporting a better quality of sleep (Valdimarsson et al. 1999).

## INTERNATIONAL COMPARISONS

One of the most crucially important consequences of the international adoption of the RAI assessment is that it has made the comparison of care—whether health care or social care—between different countries feasible. Previously, it was possible to write off such comparisons because findings could be attributed to the structural differences in systems of care from country to country. But with the RAI, for which the individual resident is the basis of comparison, many earlier problems have been overcome. Today's RAI-based comparisons give fresh insight into the variability of care, highlighting both what is well done and what can be improved upon (Fries et al. 1997).

Many examples of lessons learned in Iceland appear in the special September 1997 issue of *Age and Ageing*. The issue features comparisons between nursing homes in Iceland, Denmark, and the United States. Data from Iceland emerge from a 1994 study of 1,255 residents in Reykjavik's 11 nursing homes; Danish data were gathered in 1992–3 in a study of 3,541 residents in 65 of Copenhagen's 75 nursing homes; and U.S. data, gathered in 1993, are for 273,491 residents in nursing homes in Kansas, Maine, Mississippi, Nebraska, South Dakota, and Wisconsin (Fries et al. 1997).

The age range of the residents from whom data were gathered was similar in all three countries: about half of the residents were 85 or older. In all three countries, women accounted for about two-thirds of the nursing home population. Length of stay was longest in Iceland, where about 61 percent of residents had been in nursing homes for more than two years, as opposed to 49 percent in Denmark and 46 percent in the United States.

Good ADL functioning was most prevalent in Iceland (67 percent), compared with 63 percent in Denmark and 47 percent in the United States. In Iceland, 29 percent of residents showed no cognitive impairment; the figures for Denmark and the United States were 22 and 18 percent, respectively.

Rates of serious dementia were similar from country to country: 29 percent in Denmark, 27 percent in Iceland, and 24 percent in the United States (Fries et al. 1997).

The data showed that, in general, Iceland's nursing home population required lighter care than did nursing home residents in Denmark and the United States. One paper in the special *Age and Ageing* issue (Ikegami, Morris, and Fries 1997) tried to estimate the percentages of nursing home residents least in need of nursing home placement in each of these three countries. The results depended on the definition of "light care" used. Under a broad definition, the numbers of those in need of light care were 52, 43, and 30 percent for Iceland, Denmark, and the United States, respectively. Under an intermediate definition, the numbers were 35, 24, and 14 percent, respectively; and under a narrow definition, they were 5, 3, and 2 percent. Thus under all three definitions, Iceland appeared to have the highest percentage of light care cases, indicating that Iceland needed better rules for nursing home placement. Since the Reykjavik study was performed only three years after the introduction of the NHPA system, however, and since the majority of residents studied would have been admitted prior to its implementation, it remained unclear how well that system was working to correct this situation.

The comparison showed that 57 percent of nursing home residents in Iceland suffered incontinence, compared with 52 percent in Denmark and 46 percent in the United States. Interestingly, of those who were not incontinent, 32 percent in Iceland, 40 percent in Denmark, and 16 percent in the United States used diapers (Sgadari et al. 1997). In most cases, this may signal an unnecessary cost.

Among residents who themselves thought they had rehabilitation potential, half in Iceland and Denmark received rehabilitation therapy, as opposed to only one-quarter in the United States. The comparison showed similar results for those who had been assessed by staff as needing rehabilitation, the difference being that, in general, staff considered twice as many people as having rehabilitation potential (as compared, that is, with residents themselves). A higher percentage of disabled or cognitively impaired residents received treatment from physical therapists in Iceland (28 percent) than in Denmark (16 percent) or the United States (10 percent) (Berg et al. 1997).

Degree of social interaction may be a measure of nursing home residents' quality of life. In Iceland, 28 percent of residents did not participate in any activities, as compared with 18 percent in Denmark and 7 percent in the United States (Schroll et al. 1997). The numbers of residents who showed signs of depression but who were not receiving treatment stood at 24, 45, and 44 percent for Iceland, Denmark, and the United States, and the percentages of residents receiving psychotropic medications (antidepressants, antipsychotics, and hypnotics) were 74, 44, and 30 percent for the three countries, respectively (Phillips et al. 1997).

These results provide but a few examples of the kinds of issues on which the RAI can shed some light—issues that are relevant to the quality of care residents receive and to the cost-effectiveness of the care delivered. Results like these stimulate discussion and inform decision making (Finne-Soveri et al. 2000).



## THE RAI'S BENEFITS TO ICELAND

Why is the RAI-NH system valued in Iceland? Different parties like it for different reasons. Academicians are keen to know what the issues are and to understand the epidemiology of the nursing home setting. Because, as noted above, the RAI approach assesses the individual, it can cut through the differences among health and social care systems, thus allowing not only comparisons between institutions but also between various countries' long-term care practices. By showing how variable systems of care relate to outcomes, the RAI can reveal the best care solutions.

Icelandic institutions see the value of systematic information collection, better documentation of problems (using the so-called triggers), and the possibility that the RAI can become part of the resident's nursing and medical record. The Resident Assessment Protocols (RAPs) enable better care plans to be carried out; nursing home administrators are better able to match resources to case mix (the blend of patients with differing care needs in individual wards). The RAI also allows staff to participate in research, enhancing their job satisfaction. (A survey of head nurses that dealt with their experience of the RAI between 1994 and 1997 confirmed an overall positive attitude toward the instrument among nursing home staff; see Jensdóttir 1998.) And nursing home residents themselves have opinions that ought to be taken seriously; they enjoy the attention they receive during data collection, and that in itself is therapeutic. The RAI's focus on function and disability, as the truly relevant issues in residents' daily lives, is very important to the elderly.

Finally, Iceland's Ministry of Health appreciates several of the RAI's benefits. First among these is the quality assurance that grows out of the RAI's use nationally and internationally. The prospect of being able to base resource allocation on residents' actual needs—something that, hitherto, was difficult or impossible—is extremely appealing. The RAI permits many questions to be answered: How are elderly people actually faring in nursing homes? What are the specific issues that must be addressed? Do the services delivered match the needs of the residents? Do staff meet these needs? How does Iceland's system of long-term care compare with those of other nations in terms of cost and staffing? Are differences in resident populations mirrored in appropriate differences in reimbursements? How can we guarantee consistent quality of care? Iceland's surgeon general has approved of the system because it provides the prospect of a greatly improved quality of care and because it leads to the continuing education of all the staff involved. As a series of new RAI-based instruments—for home care, acute care, and subacute care—has developed, the possibility of a seamless system of elderly care emerges.

## CONCERNS

Some nursing administrators and nursing staff did voice concern over the length of the instrument and the time it takes to administer the assessment. In the survey of RAI use mentioned above (Jensdóttir 1998), two-thirds of the nurses felt that the data collection considerably increased their

workload. One-third felt that limited staffing would preclude effective use of the data collected. When the study was concluded in 1997, 80 percent of the nurses had not yet seen significant changes in work processes or care planning in their institutions.

A key factor in winning nurses' and administrators' approval of the RAI systems has been the extensive teaching about the use and value of the RAI system that has been led and carried out by the nurses in the *IceRAI* group. No one is allowed to use the instrument without participating in a standardized, one-day training. Currently, a significant percentage of Iceland's nurses have undergone RAI training, and the use of the RAI is now taught in a course on geriatric nursing in the Department of Nursing at the University of Iceland. Specially trained nurses offer sessions on the use of the RAI instrument several times a year for all staff members who intend to use it in their practices.

Another concern was that there were not enough trained staff to carry out such an extensive assessment in remote areas of the country. The *IceRAI* group has partly overcome this concern with site visits by members of the RAI group who have themselves made visits to these remote sites to train people on location.

#### **MANDATED USE AND SUBSEQUENT DEVELOPMENT**

The Ministry of Health mandated the use of the RAI on a national basis in 1996, simultaneously promoting the computerization of RAI data collection and distribution, a move that will lead to the generation of a longitudinal database offering great research opportunities. In late 2002, the RAI-NH was slated to become the first system to appear on the newly constructed National Health Care Intranet. This intranet is a key component of the Iceland government's policy of establishing a highly secure system for transmitting data electronically to replace the current system of sending information on paper, in which personal data protection is suboptimal.

Beginning in 1999, the ministry took the first steps toward making nursing home financing an RAI-based system. To begin with, the per diem rates received by a few nursing homes were corrected based on objective RAI evidence that these nursing homes had residents whose care needs were similar to those of residents in better-reimbursed nursing homes. (This was something that the nursing homes had long fought for.) The completely revised system of reimbursement based on the RAI will be implemented in 2003. Between 40 and 60 percent of the nursing home financing will be variable based on the 44-category Resource Utilization Group (RUG) system; the rest will be fixed, paid according to the average cost of all facilities in the previous year.

In 2002, *Sóltún*, a new nursing home, opened in Reykjavik—the first in Iceland to be run by a private, for-profit corporation. The contract for its services is largely based on the RAI/RUG system, and the nursing home is required to accept residents with heavy care needs, as defined by the RUG system (Carpenter et al. 1997; Cooney and Fries 1985; Fries and Cooney 1985; Mehr and Fries 1995). The extensively detailed contract is very much in line with the RAI system in its emphasis on quality of care. This innovation is likely to push Iceland's other nursing homes forward, both professionally

and in terms of financial accountability because both “buyer” and “seller” will see things through the same lens.

RAI use still lags in the areas of care planning, triggers, and RAPs. These important uses of the instrument should gradually become more widespread in the wake of the intranet computerization of the instrument in late 2002. As has been done since 1996, data on individual nursing homes residents is collected on a yearly basis. The accumulated data create a longitudinal database on long-term nursing home care. The Data Protection Committee has approved this centralized database. The database provides a unique opportunity for monitoring quality over time, and it will also be used for research. The privacy of individuals will be protected through the use of non-personal identifiers. To monitor quality of care under the new reimbursement system, Iceland’s surgeon general has created a specific job position. Not only will this officer be responsible for monitoring the quality of care that elderly residents receive, but he or she will also ensure the quality of data collection and will give support to nursing home staff using the instrument.

A randomized quality indicator nursing intervention study recently performed in the Reykjavik area demonstrated that outcomes can indeed be improved through educational effort and support. This was true for the various indicators studied, including prevalence of restraint use, weight loss, and untreated depression (personal communications among A.B. Jensdóttir, I. Hjaltadóttir, and H. Gu\_mundsdóttir, 2001).

Though clinical guideline development is still in its infancy in Iceland, the country is making progress in this area, as well. Many of the issues revealed by the RAI lend themselves to the use of clinical guidelines in addition to RAPs. The use of sleeping medications and psychotropic drugs is obviously a promising area for the development of clinical guidelines, as are approaches to the treatment of pain and the diagnosis and treatment of depression (to name just a few). Iceland’s experience demonstrates that the use of the RAI is just one part of an overarching reform, which will take some time to implement fully. However important the RAI is—and will be—for Iceland, it alone cannot create a sudden, complete revolution in elderly care.

#### **MDS FOR HOME CARE**

The nursing home instrument is now well established in Iceland and is here to stay. Other aspects of elderly care, however, remain as incompletely understood as nursing home care was before the introduction of the RAI-NH. Health care policy allows the elderly to stay at home as long as possible and supports them in doing so, but the needs of those in home care are not well defined. There had long been interest in studying other forms of elderly care when such opportunities would arise, and so in 1997, when the RAI-HC instrument became available, the *IceRAI* group carried out a pilot study of home care in Reykjavik (Morris et al. 1997).

Using the RAI-HC, trained members of the research group gathered descriptive data on elderly people in home care at four community health centers in Reykjavik. Those assessed included 257

individuals (202 women and 55 men), all aged 65 years or older, who received home care in the autumn of 1997. The mean age was 82.7 years. Short-term memory deficit afflicted 36.7 percent of the individuals studied, and researchers noted a depressed look and a feeling of depression in 18 percent. Twenty-seven percent were always alone during the day, and 21 percent reported feeling lonely. Approximately 40 to 60 percent needed a good deal of help in instrumental activities of daily living. Almost all were independent in personal activities of daily living, although 53 percent needed assistance with bathing. Eighteen percent had not been outdoors for the previous 30 days. Daily pain was seen in 47 percent; pain was bad or intolerable in 32 percent. Strikingly, many of these individuals (47 percent) assessed their health as poor. On average, they received formal care for 12.6 hours during a given two-week period. Medication intake was considerable: 34 percent took more than nine medications. Twenty-three percent of the elderly in home care took anxiolytic medications; 32 percent took antidepressants; and 32 percent took hypnotics.

The study showed that about half of the home care cases in Iceland were light care cases, which contrasted with the situation in Italy and Japan, where a higher proportion of home care patients had significant cognitive and motor impairment (personal communication with Roberto Bernabei and Naoki Ikegami). The use of medications in general—and of psychotropic medications in particular—is higher in Iceland than in these two countries, mimicking the pattern (discussed above) that obtains in Iceland's nursing homes (Morris et al. 2000). It therefore appears that the relatively high use of medications in Iceland originates in the high utilization in ambulatory care, which is then maintained in the nursing home setting.

The study raised some questions about the quality of home care. For example, people in home care seem to have more physical symptoms that, though potentially treatable, are going untreated than do nursing home residents. This may be due to the fact that there is less teamwork in the home care setting. The typical home care recipient may go for long periods without seeing his or her physician. Because so many are lonely and never get out of doors, one may wonder if the policy of having people stay at home as long as possible is the right one. If it is, it appears that the home care system should attend more carefully to issues of loneliness, depression, and mobility out of doors, perhaps by organizing elderly volunteers who could support their less-healthy peers. Most of the arguments for implementing the RAI-NH can be convincingly applied to the RAI-HC. At the time of this writing, a subgroup of *IceRAI* is conducting a study of home care throughout Europe, called ADHOC (for the AgeD in HOME Care project). This study should enable us to better envision how the RAI-HC can be implemented to benefit the elderly at home and those who provide them with care.

Progress is also being made toward the eventual implementation of the other instruments in the RAI family, including instruments for assessing acute care, mental health care, post-acute care, and palliative care. A Nordic study now in progress is looking at the use of the acute care instrument in all five Nordic countries. In Iceland, a group within the Department of Psychiatry at the University Hospital in Reykjavik is conducting a pilot study on the use of the mental health care instrument. It is

too soon to tell what will happen with the palliative and post-acute care instruments, but there is palpable interest in these instruments, as well.

#### **USE AND LIMITATIONS OF THE RAI SYSTEM**

Policymakers responsible for the care of the elderly have to achieve multiple goals simultaneously: high quality of care, cost-effectiveness, a system that functions comprehensively, and the optimal use of resources. In a well-managed system, people are placed in settings that give them the optimal level of care at the lowest cost while ensuring that quality of care achieves the standard that the quality indicators are meant to secure. Professional fulfillment is also an important aspect of a well-managed system.

The RAI addresses many of these issues, but further development of the assessment system is needed. Issues that are well covered by the RAI system include the financing of elderly care, resource utilization, and quality indicators. The RAI system enables the identification of people who have been placed in the wrong settings, and it will likely optimize the placement of elderly people, since financial incentives can be generated within the RUC system. For example, because heavy-care patients will generate more resources for nursing homes, the “bed blocking” issue will in all probability be resolved.

Despite its objectivity, however, the RAI system in and of itself cannot define optimal care for the elderly, nor can it measure quality of life. Once these terms have been defined, however, the RAI system will make it possible to tell how well we are doing in these domains. The suffering of the elderly—whether in nursing homes or home care—compels us to define optimal and acceptable care in explicit terms. How great a prevalence, if any, of pain or depression is acceptable? This kind of question can only be addressed through professional debate, but the use of the RAI system will help us see how well we reach our goals using different interventions. Are our instruments able to define the best placement of the elderly in the service chain? Once the seamless RAI assessment system has been realized and the condition of the elderly in each of the service system’s components has been identified, new opportunities for understanding will be attainable. Both internal comparisons within national systems of care and cross-national comparisons will further aid in this regard. Deepening our understanding of the best placement of the elderly person at any point in time will be of crucial importance to all concerned (Hirdes et al. 1999).

The major strength of the RAI system lies in the assessment itself. Though the system promises improved care planning (and thus improved care), this part of the system remains less developed than the assessment. On one hand, existing resident or client assessment protocols need to be constantly revised according to best evidence available; on the other, we need to be sensitive to issues that the assessment does not cover at all—including quality of life and the promotion of care planning in daily practice. Extensive and continuing education is likely to be of importance here.

Currently, each RAI assessment is carried out by a single professional. Because teamwork is so important in effective elderly care, however, it may be that professionals representing different disciplines should cover specific parts of the assessment and then communicate about care planning

as a team. The information accumulated by the RAI system is very sensitive and personal. It is therefore of paramount importance to protect the data from access by anyone not directly involved in the care of the elderly.

## CONCLUSIONS

The introduction of the RAI system in Iceland may have been helped by the fact that the country's population is small and homogeneous. This, however, is by no means the only reason that the RAI has been implemented so successfully. The success of the RAI-NH in Iceland has also relied on a few crucial tactical decisions. These were the decisions to form a national steering committee based in the Ministry of Health and to mandate the RAI's implementation only after a pilot study had been done and nursing home staff had been trained in the instrument's use and introduced to the benefits it potentially offered. Moreover, the mandated implementation has been followed by ongoing support and by the computerization of the data. Among Iceland's health care sectors, the nursing home industry now stands at the forefront of computerization, which in itself is likely to raise the self-esteem of those who serve in this hitherto underappreciated service sector.

To summarize, we in Iceland can say that we got the right instrument at the right time because we had the right people in the right places, and that "bottom-up" and "top-down" approaches to implementing innovations in this service sector have converged in the middle. This is a case where the core elements of geriatric services—interdisciplinary assessment and teamwork—have come to the fore. As a result, Iceland's system of elderly care has permanently changed.

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**MDS (MINIMUM DATA SET) ASSESSMENTS FOR POLICYMAKING  
AND EVALUATIONS IN ISRAEL**

**Jacob Gindin, Sara Levi, Orna Intrator, and Jochanan Stessman**

**EXECUTIVE SUMMARY**

Israel has witnessed a rapid growth of its elderly population (twenty-fold over the last five decades), and public health policy, especially in the last two decades, has been unable to keep pace with the pressing needs of this expanding population.

In establishing public health policy, policymakers first determine major goals, then allocate resources. Standards of care, created in conjunction with the education of health care providers, follow, and room should subsequently be made for research and comparative studies.

The Resident Assessment Instrument and Minimum Data Set (RAI-MDS) tools are applicable to many health care settings and have been shown to hold great potential for the development of evidence-based medicine (Bernabei et al. 1999). The clinical, demographic, and utilization data generated by systematic assessments provide means for targeting specific populations for global policymaking and quality assurance. These same tools are likewise important for establishing equitable reimbursement policies (rates and scales) and for monitoring and assisting with quality management. Comparative MDS particulars based on nursing homes (NHs) in the United States, home care (HC) in Italy and Japan, and in post-acute care (PAC) in Canada provide important evidence regarding the applicability and feasibility of such projects in Israel. Further, the RAI-MDS tools establish a basis for communication between health professionals that is valuable in the education and training of quality health care providers.

The RAI-MDS system is being implemented in Israel through the utilization of three instruments: the MDS-NH 2.0, the MDS-PAC 1.0, and the MDS HC 2.0. The instruments have all been translated into the Hebrew language and modified to suit the national environment. The implementation is occurring in both institutional and community settings, and, in each setting, is based in specifically dedicated centers. (Two of this paper's authors head these centers.)

The triangular approach to MDS implementation (the TAMI model), which encompasses education, policy, and services, is the vehicle for implementation in institutional settings (nursing homes and geriatric post-acute hospitals). The model emphasizes education and training of skilled professionals and fosters the collection of comprehensive assessment data that will serve for quality assurance and for future policymaking.

Several demonstration studies have tested the application of the TAMI model in institutional settings in Israel. The experience gained in these pilot studies may help in future full-scale implementation throughout the country. The pilots placed emphasis on using the RAI instruments to acquire adequate data while documenting population characteristics and needed services. A prime objective was to develop a common language that could be used by health care and social welfare providers.

Once analyzed, the information that emerges from these pilots may help facilitate integration of services both in the community and in institutions. The RAI family of instruments will be used as the basis for assessing the elderly, using standardized tools. We hope that information obtained through these instruments will help guide policymakers and professionals in providing adequate

and acceptable services to the elderly population at lower cost, while minimizing confusion and reducing bureaucracy.

## **INTRODUCTION**

Israel's population, which now stands at about six million, is extremely heterogeneous in ethnic, immigrant, socioeconomic, and religious aspects. The country's percentage of elderly people (65 years of age and older) is lower than that in most Western nations, currently amounting to 10 percent of the population, with an expected rise to approximately 12 percent in the next 20 years. Only 3 percent of the non-Jewish population is elderly, however, while 16 percent of the more recent immigrants from the former Soviet bloc are elderly (Brodsky, Shneur, and Be'er 2000). The proportion of the oldest old in Israel is high; unsurprisingly, these Israelis have high levels of disability (Fuchs et al. 1998).

In 1995 the Israeli parliament, the Knesset, passed the National Health Insurance Law, encompassing all residents of Israel. As mandated by this law, the Israeli state provides health care services including all acute and emergency physical and mental inpatient care, outpatient and ambulatory medical help, physician office visits, specialist consultations, regular nursing care in clinics, home care nursing, and (to a certain extent) laboratory tests and medical imaging. The government also pays for a pre-negotiated list of medications. All these services fall under the jurisdiction of the four Sick Funds (the Israeli equivalent of HMOs), which are allotted payment according to an age-based per capita rate. Health care services are financed through income-based taxes paid by both employees and employers. The 1995 law deferred decisions regarding the financing and structure of long-term physical and mental care services to a later date. Several communities have tried to formulate recommendations to hasten realization of this part of the law, so far without result.

As in many countries, Israel's system of long-term care for the elderly is highly fragmented in terms of care providers, regulation, and financial responsibilities. It involves several national government authorities (the Ministry of Health, the Ministry of Labor and Social Affairs, the National Insurance Institute, the Sick Funds), local municipalities, and various charitable organizations. The spectrum of long-term institutional care includes nursing care for physically frail and demented elderly individuals, board-and-care facilities for demented persons, and complex nursing care for post-acute and acutely ill nursing home residents.

The Ministry of Health regulates nursing home care for clients requiring light to moderate levels of nursing and for demented patients. At the time of this writing, this service was being provided to more than 15,000 residents in 288 institutions. The cost of care for about 9,500 of these long-term care patients was covered mainly by the Ministry of Health.

The Ministry of Health (whose regulatory system is separate from that of the Ministry of Labor and Social Affairs) has two regulatory bodies overseeing the long-term care facilities that treat and look after the physically disabled and mentally frail elderly. The first regulatory body, part of the ministry's Geriatric Division, operates on a national level, conducting its surveillance through a team consisting of a nurse,

a physical therapist, an occupational therapist, a social worker, a nutritionist, and an administrator. The teams presently use various instruments, some of which are still in the process of formation.

The second regulatory system, part of Public Health Services, operates on a regional level through 15 local health bureaus in six districts. Regional-level inspections are conducted by a team consisting of a nurse, a social worker, a physician, and a special health hazard inspector. These inspections use tools that are different from the ones used by the national team. The difference lies in the fact that the first ones inspect processes and outcome, while the second ones check for the existence of many items that are mandatory for licensing a facility.

Besides those patients already mentioned, Israel has about 2,000 “complex nursing” patients who have elaborate care needs and require skilled nursing facilities (SNFs). The Ministry of the Treasury, through the Sick Funds, pays for most of the care received by these patients, though such care is covered only for limited periods of time.

Some Israeli elderly receive care at home. Financing by the Ministry of Labor and Social Affairs and by local municipalities provides assistance to frail clients, living in the community, who require help with activities of daily living (ADLs) but only minimal help in personal care. A limited range of social support is provided by the local municipalities but financed by the Ministry of Labor and Social Affairs. Personal care for disabled persons is provided by the Community Long-Term Care Insurance Law. A 1965 law (the Old Age Homes Law) addressed the supervision of institutional residences, formulating standards of care and mechanisms for regulation. This law was inadequate because it did not recognize the importance of medical, cognitive, and physical causes of frailty. Assistance with ADLs for community-residing clients was mandated by the 1988 Community Long-Term Care Insurance Law. Home care agencies provide this assistance to eligible clients (who now number approximately 105,000), and the National Insurance Institute (NII) manages and pays for the program.

Because of the system’s fragmentation, clients often have no choice but to seek assistance simultaneously from several providers, even as they are mostly ignorant about the myriad of services, regulations, and requirements governing these separate bodies. Another consequence of this fragmentation is the multiplicity of bureaucratic mechanisms, which quickly frustrates patients and their families. Repeated applications and delays cause loss of personal time, and services provided during the overlong waiting time for the appropriate service are often inadequate (Gindin et al. 1998; Gross, Rosen, and Chinitz 1998).

As mentioned earlier, the 1995 National Health Insurance Law deferred negotiations on the responsibility for long-term care to a later date, with the intent that this service, like other health care services, would ultimately be provided by the Sick Funds, which determine eligibility by need. Because the law, as it stands, fails to cover institutional long-term care, government subsidies for this service are allocated in a cumbersome fashion and reach the needy slowly, often in dribs and drabs.

The two routes of Minimum Data Set (MDS) implementation presented below were attempts to find solutions to the problems of fragmentation of the services for the elderly, diversity of available services, and inconsistent quality of care.

## A TRIANGULAR APPROACH TO RAI IMPLEMENTATION

### The Triangular Framework

The conceptual framework guiding RAI implementation in Israel is triangular, based on interaction and cooperation among the policy, education, and service infrastructure arenas. At present, the Israel National Institute for Health Policy and Health Services Research supports two projects in nursing homes and in post-acute geriatric care. These projects were empowered through the triangular approach mechanism. They included the important work of the national NH and PAC steering committees. The Laboratory for Research in Gerontology and Geriatrics at Haifa University and the Geriatric Institute for Education and Research at the Kaplan Medical Center created and presently operate the NH and PAC infrastructure, pilot programs, and research.

Research, an integral part of the triangular model through which RAI implementation is promoted in Israel, covers the entire process, from the planning stage through integration, analysis, and assessment of data. Research findings are handed to the “triangle’s components” in the steering committees, which use them for future planning and decision making.

In conformity with the triangular model, the two national steering committees comprise representatives of key national policy, education, and services groups, as follows:

1. *Policy-oriented representatives* include government policymakers in geriatric medicine and nursing, members of the board of the Israel Geriatrics Society, and members of the National Geriatrics Council of the Ministry of Health.
2. *Education-oriented committee members* include representatives from the Kaplan Medical Center’s Geriatric Institute for Education and Research, the Kaplan Academic School of Nursing (affiliated with Hadassah and Hebrew University, Jerusalem) in the same center, and the Laboratory for Research in Gerontology and Geriatrics at Haifa University.
3. *Services-oriented members* (including those in research services) include the directors of nursing and medicine at the Harzfeld Hospital (where the MDS-PAC implementation pilot study was carried out); staff of the Geriatric Institute for Education and Research (which supplies the program’s services and infrastructure and serves as its data repository); staff of the Laboratory for Research in Gerontology and Geriatrics at Haifa University, and representatives of the Soroka Medical Center and the Ben Gurion University (BGU) Medical School in Beersheba. Representatives of the JDC-Brookdale Institute, which operates a sister program of MDS-HC, participate as observers.

### The Policy Component

Israel has five levels of long-term care (LTC) facilities. The first three levels of LTC facilities are controlled and supervised by the Ministry of Labor and Social Affairs. The first level accommodates

the independent elderly. The second is assisted living for minimally frail patients. The third level takes care of patients with more demanding conditions, who require IADL care nursing and some part-day care. Those are characterized as “the mildly frail” or “the exhausted.” The highest two levels of LTC facilities are controlled by the Ministry of Health. The fourth level includes nonskilled LTC facilities caring for those who need continuous care and are physically and mentally disabled; they are stable but highly ADL-dependent. The MDS-NH is relevant to this level. The fifth level treats patients belonging to the most demanding category, “complex nursing.” The Ministry of Health supervises this level, and the Sick Funds pay for this care, though with some financial participation by patients’ families.

Independent living and assisted living are mostly privately supported. Complex nursing is mostly public (NFP) or owned by the government. Within nursing care there are 288 facilities with 16,000 beds. They are nearly half private and half NFP. The facilities for the “exhausted” or “the mildly frail” are usually small. About 100 of them are adjacent to nursing care facilities, and in this way, form a new hybrid called a “joint institution.” Part of the beds in such a facility are paid by the Ministry of Health, and part by the Ministry of Labor and Social Affairs.

Governmental policy aims at assuring provision of suitable services in a system that has struggled perpetually with a shortage of economic resources, especially during the last few years. The Ministry of Health’s Geriatric Division deals with the main problems of nursing care and complex nursing; it sets and enforces standards and it regulates and budgets most of the beds.

Surprisingly, the government stills owns and operates part of the beds it inspects. The LTC system is somewhat cumbersome, with lack of continuity of care between components and with a low level of flexibility in structure and function. An additional problem is the hard feelings of professionals in the field regarding priorities within health care and status among health professionals. Above all, there are eight modes and systems of inspection within the above-mentioned five components of LTC. Some of them are national; others are regional. The inspection modes are carried out by out-of-system agencies. Adopting the interRAI concept in institutional services and implementing the MDS system in post-acute geriatric hospitals and nursing homes will address the latter problem by creating a way to systematically measure and control services on a nationwide scale.

The goals of MDS-NH, achieved through the balanced triangular approach described above, are as follows:

1. To adequately define what nursing care for institutionalized patients should consist of
2. To improve the quality of professional, medical, and nursing care and to increase the efficiency of manpower utilization through the definition of health-related problems, evaluation and assessment, intervention, and allocation of resources
3. To establish a database that will enable the comparison of clinical groups in different institutions and in different geographical regions of the country
4. To initiate and promote research projects dealing with diverse aspects of geriatrics and gerontology

5. To gather information about nursing care and medical treatment and to use it to promote sound decision making and innovative solutions in the clinical, administrative, and policymaking domains

### **The Educational Component**

The educational component of the triangular approach includes activities conducted by the Geriatric Institute for Education and Research at Kaplan Medical Center, the Kaplan Academic School of Nursing (affiliated with Hadassah and Hebrew University, Jerusalem), and the Laboratory for Research in Gerontology and Geriatrics at Haifa University.

The introduction of the RAI included, in the first stage, the application of the MDS-PAC in Harzfeld Hospital, which provided a suitable environment with highly skilled academic personnel. The second stage consisted of the implementation of the MDS-NH 2.0 through an educational program to train trainers who will professionally lead the MDS-PAC and MDS-NH processes.

The “train the trainer” course included two training days: (1) a theoretical day, including familiarization with the tools, and (2) a data-gathering day in a geriatric institute. This course was preparatory to a broader data-gathering program in geriatric institutions in the center and south of the country.

It is difficult to separate development from training, but it is possible to distinguish between these two functions. *Training* refers to education in specific skills, while *development* means the growth of capabilities and skills that the employee needs to function within an organization. Training of staff is not a luxury (Gloverson and Carmi 1983). It is a prime agent for promoting organizational survival and ensuring good performance. The training centers at the above-mentioned institutes provide appropriate support for the professionals involved in the implementation of the MDS in Israel.

From the outset, the national nursing home and post-acute care steering committee emphasized that the educational component of the MDS implementation would be as important as the policy and infrastructure components. In its MDS training, Israel has adopted the “fan” model developed at the Free University of Amsterdam, which calls for the establishment of learning centers, attached to academic institutions, at which key representatives from geographically dispersed nursing homes can receive training. These trainees subsequently operate local training and support systems in their own facilities, with the help of the national centers.

Six LTC professionals, “the Amsterdam group,” traveled to the Netherlands for a four-day “Train the Trainer”/“Train the User” program at the Free University of Amsterdam in February 2001. The team was drawn from the Kaplan Medical Center’s Geriatric Institute for Education and Research, the Kaplan Academic School of Nursing, and the Geriatric Division of the Ministry of Health. They were trained by experienced interRAI members of the Netherlands.

The first training program in Israel took place in spring 2001. The core of teachers included the graduates of the “Amsterdam group.” The trainees included 30 head nurses of geriatric hospitals and

departments from 20 different institutions. They aimed to become MDS-NH trainers within their facilities. The second group that was trained for this program consisted of students of a post-basic course in geriatric nursing, which prepares practicing registered nurses for leadership tasks in LTC. The MDS training was part of their curriculum, and they participated in collecting MDS-NH data later on.

The authors of this report and some of the members of the steering committee have also presented the MDS concept and tools, as well as the experience gained so far, at a variety of national conferences, including meetings of the Israel Geriatrics Society, the National Health Policy Institute, and the Geriatric Nursing Directors Circle. Further educational efforts will include training of administrators and the presentation of the MDS instrument to policymakers around the country. There have also been two conferences—one for medical professionals and one for service suppliers.

### **The Services and Research Infrastructure Component**

Developing an integrated MDS infrastructure for users and trainers according to the triangular model will provide accessible training materials and programs, furnish user-friendly computer programs, and enable inter-institutional linkage. The infrastructure component includes

- Coordination of courses, distribution of teaching materials, and dissemination awareness to the MDS within the LTC system
- Translation of instruction manuals and accompanying materials into Hebrew
- Computer programming support
- A database and data analysis for institutes, policymakers, educators, and researchers
- Connection with interRAI organizations on a national and international level

### **RAI IMPLEMENTATION**

Israel has begun initiating RAI programs. At present, a number of organizations, nursing schools, and nursing facilities are either studying the MDS tools or have implemented and are using them. Many in the LTC field, however, still do not recognize the benefits of these assessment instruments, and some even oppose them. This opposition is mainly by people who have not had direct experience with the instruments, have their own facility habits, and are worried because of the professional demands that the MDS creates, which has an impact on manpower time during the first steps of implementation in a facility.

The RAI infrastructure in Israel is based on the American, Canadian, and Dutch experience, though it has been adapted to fit the Israeli context. At the time of writing, the MDS was being integrated with patients' records to enable "friendly" system operation and enhance connections between projects and disciplines, between departments and hospitals, and between national bodies and local institutes. This infrastructure will give all of those involved in the RAI system in Israel support for current MDS implementation and related programs as well as future undertakings.

Within the framework of government planning, the Inter-Ministerial Committee for Restructuring the Elderly Services in Israel has recommended use of the MDS tools.

### **Harzfeld Hospital Implementation**

Harzfeld Hospital carried out its MDS-PAC implementation in several stages:

1. In May 1999, one department initiated the Pilot 1 MDS-PAC scheme, with the head nurse and senior physician coordinating the project. Using clinical PAC criteria, they chose suitable patients to participate in the pilot. The MDS was introduced to the nursing staff, who studied the proper way to fill out the forms and who received guidance in documentation methodology. A PAC program quality controller and the head nurse constantly supplied support and feedback. The pilot emphasized the need to minimize the phenomenon known as missing variables. After a primary analysis of the data, the steering committee gave individual feedback to the head nurse and medical director of the facility, who then passed it on to relevant staff members. Jacob Gindin presented the MDS-PAC goals, associated problems, and results to the board and administrative staff of the facility.
2. In October 1999, a second department started the MDS-PAC. At the weekly staff meetings, professionals described patients' progress using MDS-PAC terminology.
3. In January 2000, a third department introduced the MDS-PAC.

### **Nursing Home Reimbursement Study**

The 15,082 long-term care beds in Israel are mostly under the aegis of the Ministry of Health, which has an annual budget of approximately 800 million shekels (about US\$189 million). This budget helps subsidize the care of nearly 9,500 nursing/demented patients. Complex nursing care (approximately 2,000 beds) remains the responsibility of the four Sick Funds. This artificial division creates problems for the patients and their families and wastes resources, since the difference between the two separate systems has only to do with the kind of nursing care patients receive (Bentur et al. 1998).

The distinction between nursing/demented patients and those who require complex nursing care is currently determined by a set of rules that was developed in an ad hoc way, based on clinical experience. A patient is considered to be a complex nursing case if his or her condition is characterized by one or more of the following five criteria:

1. Axial or sufficiently voluminous decubitis ulceration
2. Feeding by nasogastric tube (as opposed to gastrostomy or jejunostomy tubes)
3. Constant oxygen therapy
4. Oncologic disease that is responsible for the dependence on nursing care
5. Constant physician availability necessary



Many nursing patients with active medical problems, however (including those with recurrent infections, congestive heart failure, and metabolic instability), require the same complex care as those suffering from the conditions listed above. Patients defined as needing complex nursing are treated in specific units, located in only a few institutions. Thus, patients who change care status from complex nursing to nursing/demented often need to change location, and the relocation stress they endure imposes additional emotional suffering. Meanwhile, the Ministry of Health and the Sick Funds are often at odds regarding which agency is responsible for which patient.

The Ministry of Health's Geriatric Division, which is responsible for nursing home care, is looking into using evidence-based criteria to set a sliding scale for daily rates—one that will take institutions' care loads into account and that will reimburse, in part, based on quality outcomes. All these issues underscore the need for the development of a case-mix adjustment system for institutional long-term care in Israel.

A research project directed by Jacob Gindin and Orna Intrator has collected MDS 2.0 data on residents in approximately 40 nursing units, as well as staff time in care in some of these units. The project will establish an evidence-based definition of complex nursing patients, based on the characteristics of the 15 percent of patients who require the costliest care. The project's aim is to develop a case-mix index for institutionalized LTC patients that is appropriate for Israel. This index would aid institutional managers in making informed decisions regarding their facilities and would assist the government in setting evidence-based policies with respect to reimbursement of LTC services.

## **MDS INSTRUMENTS IN COMMUNITY SETTINGS**

Home care is a rapidly developing health care system, providing a socially desirable and usually less expensive alternative to conventional institutional care.

### **The Community Long-Term Care Law**

Since 1988, Israel has provided long-term home care to community-residing elderly who meet certain eligibility criteria. Community Long-Term Care Insurance (CLTCI) is managed by the National Insurance Institute (NII), which has an annual budget of 1.6 billion shekels (about US\$378,250,000). Specially trained nurses screen applicants, and services are assigned by local committees whose members include representatives of NII, nurses of the general Sick Fund, and a social worker from the local bureau of social services. The benefit is for in-kind services and is paid directly by NII to home-care agencies that employ the nursing aides.

During the first decade of the CLTCI law's existence, the number of beneficiaries increased steadily, from over 16,000 in 1988 (4.4 percent of Israel's elderly at that time) to more than 85,000 in 1999 (about 11 percent of the elderly population) and 106,000 in 2002 (16.1 percent of the elderly population). Most of the increase in number is due to increasing awareness. The characteristics of

CLTCI beneficiaries appear to have changed over time. The greatest increase is in the mild to moderate level care recipients (6–11 weekly hours). There is also an increase in recipients with moderate dementia and in immediate post-acute care after discharge from the hospital. The information collected routinely by NII is obtained as case review for acceptance into the home care program. The review primarily consists of itemization of physical functioning, demographic information, medications, and past hospital utilization, and includes a limited needs assessment. There is, however, a growing need to evaluate the program regarding expected duration of service use and whether the program is beneficial in preventing deterioration of functional impairment and preventing or delaying institutionalization and subsequent mortality.

In many instances, home care is the first step in long-term care. The community-located service aims to prevent or prolong further decline in physical functioning and cognition. To obtain optimal results, the service provision must include nursing, and personal care, as well as IADL elements. Currently, the CLTCI law provides for personal care and homemaking support for the disabled elderly, easing family members' burden. The package of services also includes daycare centers, laundry services, and the provision of alarm systems and disposable medical equipment.

There is a growing awareness within the NII that the CLTCI program should be evaluated, over time, based on more detailed characteristics of applicants and beneficiaries. A planned NII project directed by Orna Intrator and Catherine Berg from Brown University (U.S.) and Jenny Brodsky and Neta Bentur from the Brookdale Institute (Israel) will assess a sample of 3,000 applicants for CLTCI using the MDS-HC instrument. The MDS-HC collects comprehensive information about a person's cognitive functioning, communication abilities and hearing, mood and behavior patterns, social functioning, informal support, service utilization, physical functioning, diagnoses, medications, health conditions, nutrition, skin condition, and environment.

Reassessment of eligible beneficiaries will take place after 2, 6, and 12 months. Information on care plans, services provided, nursing home placement, and all inpatient hospital admissions, emergency room and ICU treatment, and mortality will be collected throughout the course of the study. The primary policy and research objectives of this project are as follows:

- To examine the utility of assessing applicants using the MDS-HC compared to the existing instrument
- To check whether it is possible to define more sensitive indicators, which will help NII refine eligibility criteria
- To examine existing criteria for determining short-term eligibility and determine whether additional criteria might exist that would be predictive of short-term needs
- To examine existing criteria for reassessment (after 6 and 12 months) to enable NII to target reassessments more precisely
- To examine unmet needs of the eligible population to help the system develop and determine service priorities
- To better understand predictors of impairment in this population to further the development of preventive policies

- To detect those among the eligible population who are at greater risk of hospitalization or nursing home placement

This study will also help to build a common language for communication across professional (social and medical) boundaries. A further benefit will be the promotion of greater personal involvement of clients in their care planning and in actively seeking preventive care, which will ultimately lead to better quality of life for Israel's elderly.

### **Home Hospitalization**

Home Hospitalization (HH), the acute branch of home care, has been developed in several countries other than Israel. Ferguson (1993) describes an extramural "hospital" in New Brunswick, Canada, that provides home care services for palliative care, short-term active care, continuing care, sustaining care, and supervisory care. Funlop, Hood, and Parsons (1997) reviewed five hospital-at-home (HAH) models in London. They outline several managerial and professional difficulties with HAH and emphasize that it should be part of a continuum of services rather than an isolated care provider. Others (Leff and Burton 1996; Leff et al. 1997) discuss the potential merits of an HAH system for select populations; they established an experimental home hospitalization program in Baltimore, Maryland. More recently, Cella, Barone, and Palummeri (1999) reported on a similar model in Italy.

The Jerusalem HH program is a unique local project, characteristic of the services in Israel. Patients admitted to this program receive treatments such as optimization of medical and pharmacologic care; treatment of decubiti and other wounds, including débridement, drainage of superficial abscesses, and hydrocolloid and other special dressings; IV therapy including antibiotics, hydration, total parenteral nutrition, diuretics, and narcotics; abdominal paracentesis; enteral feeding by gastrostomy or nasogastric tube; rehabilitation following cerebral vascular accident (CVA), orthopedic procedures and injuries, heart surgery or coronary artery disease; and supportive therapy for terminal patients and their families with oncologic, neurodegenerative, and other severe diagnoses. Patients are referred to the program by medical staff of the home care unit, while in the hospital emergency room, or in the community by family physicians. Comprehensive assessment data are not available.

Steel, Leff, and Vaitovos (1998) reviewed the Jerusalem HH program and concluded: "This exceedingly well organized service, which is coordinated with those in other settings, including the emergency department, will likely serve as a model for many locations." In the emerging spectrum of acute medical care provided at home, the Jerusalem experience seems to have established a place of prominence, which, if studied in depth, could provide the essential building blocks required for implementation of similar programs. To enable this to happen, however, it is essential to collect comprehensive data that links information on (among other things) diagnoses, functional and cognitive impairment, general health status, and other clinical matters, including services and treatments in a manner that allows results to be compared to those obtained in other settings and other countries.

## **Restructuring Committee for Health Care Services for the Elderly**

Since the above services are fragmented among many agencies, three governmental bodies, and four HMOs, a committee for restructuring of services has recently proposed to the Knesset a method for integrating services that would maintain current bureaucratic structures. The proposal insists on establishing better models of communication between agencies. To that end, it suggested a uniform tool to assess income and resources of the patient, as well as patient assessment that uses a set of accepted instruments. The committee suggested the MDS for this purpose. It also recommended joint staff meetings and better communication between the different services.

The proposal's goal is that patients and their families first go to a general office that can link to the proper avenues of care. After collecting administrative data, this office will create a file on a person, available to all relevant offices. Data will be continually updated. As agencies gain experience in working together and sharing assessments, a unified evaluation tool of needs will develop. Such a scale may enable recommendation on whether a client should reside at home or in an institution. Referrals to nursing homes would determine the appropriate type of long-term care.

Two communities, Jerusalem and Haifa, have initiated a two-year model program. The MDS-HC instrument will be available to those sites for use in assessing applicants and their needs. These trial programs will investigate whether services are provided adequately and efficiently and whether the public and providers are satisfied with this triage system. The trial programs will also measure ancillary services such as hospitalization rates, physician visits, and prescription drug costs.

## **A NEW ERA**

The 1995 National Health Insurance Law and the capitation payment system created a new era in health care in Israel, requiring better administration and accountability in the handling of client conditions and care. Clearly, comprehensive data on patient conditions would enable better monitoring of quality of care and improved health care delivery systems; it would certainly help in the development of appropriate reimbursement strategies. There is therefore a great impetus for gathering quality data and conducting detailed health policy research. The RAI family of instruments clearly constitutes a suitable vehicle for assessing clients in the various parts of the system and maintaining a high degree of intersystem communication.

The law established the Israel National Institute for Health Policy and Health Services Research, whose mission is to study the effects of the law and to keep abreast of the changes it creates. The institute has funded the two institutional MDS programs: the pilot MDS-PAC feasibility study and the comprehensive MDS-NH project. Clearly, establishing case-mix reimbursement for patients, paid for by the Ministry of Health, is in line with the law, as is the definition of complex nursing patients. The institute, however, has also understood the advantages of obtaining comprehensive assessment data on

geriatric rehabilitation patients, in monitoring the quality of care, and, perhaps, in establishing a case-mix system for nursing homes.

The demonstration studies now under way in Israel aim at improving the ways of determining which people should receive benefits from the CLTCI; which recipients should be reevaluated, and at what intervals; and which patients should be classified as requiring complex nursing. These studies are motivated by reimbursement issues (case-mix reimbursement of nursing homes, targeting based on relative costs), but they also aim to provide comprehensive assessment data on the health status of Israel's sick and disabled elderly.

### **Problems in MDS Implementation**

#### *Community-Related Problems*

The implementation of the MDS in the community setting in Israel is difficult both demographically and geographically. Presently NII contracted with visiting nurses' services to conduct the evaluations for NII to determine eligibility for admittance to the CLTCI program. These nurses also conduct MDS-HC assessments duplicating the mandatory existing CLTCI test. They will also return to assess eligible individuals at designated times. This method requires prior testing to ensure that the two tools' criteria for eligibility will not disagree. Superimposing the combined RAI instrument on the home hospitalization program population requires a different view since the needs and services are more medical and professional, including doctors and RNs. Ideally, the MDS forms should be completed by a physician and a nurse working together.

#### *Institutional Problems*

Those involved in MDS implementation in Israel foresee a time when the instrument will supply comprehensive information on care for the elderly, facilitate decision making, and promote quality in the clinical and administrative areas. Meanwhile, however, implementation of the MDS in the macro (policy) and micro (geriatric institutions) environments is a slow and gradual process.

Quality control, a central conceptual frame at every level, is needed to lead and implement change. Such change may, without caution, result in organizational crisis, causing conflict and mood fluctuations among professional groups. The reasons for opposition to change are numerous: a reluctance to change the status quo, a lack of understanding among staff of the need for change, fear of failure, and fear of an additional burden. The triangular approach to MDS implementation in Israel puts a special emphasis on the nurses' training process by building a group of national trainers (based in the Kaplan Academic School of Nursing and the Geriatric Institute for Education and Research at the Kaplan Medical Center), and on the national steering committees. These national trainers are the main "outsider" agents for change.

Another element that casts its shadow on the plan is a fear among clinical professionals and administrators of "overtransparency" of the system to the outside world. There is also a threat of

creating rigid templates, which may lead to too-strict care protocols and the loss of room for “professional creativity.”

It is not always clear to professionals that the MDS is a base structure that can, in fact, be used creatively. Professionals at all levels are sometime reluctant to adopt the “one-sided” tools developed by policymakers and administrators, who are not always aware of the extent to which professionals must fine-tune. Such problems can be avoided with intelligent use, full cooperation, and good will.

A major concern of the “triangular” steering committees has been to bring together as many disciplines and groups as possible—and to anticipate all the factors affecting the MDS implementation—in order to decrease friction, obstacles, and fears and to enable the system to benefit from the advantages of this new era.

#### **CONCLUDING NOTES**

The MDS will be integrated as a tool in the national planning scheme for the following reasons:

- To foster improvement of care in geriatric institutions
- To permit uniformity of care planning according to patient needs
- To provide data on care quality control at the macro and micro levels
- To allow comparison between professional groups and between service suppliers, both nationally and internationally

The current state of affairs in the country, coupled with the many demands on the health care delivery system, however, do not allow the MDS to be utilized to the fullest extent (i.e., the “top-down” approach). Nevertheless, the authors and their teams are continually striving to introduce this important instrument throughout the country, although we do fear that it may take more time than we judge reasonable. We have no choice but to introduce the MDS and its various tools in a step-by-step way (the “bottom-up” approach) and at a slower pace than we had envisioned.

A very promising event, however, has occurred in the educational domain: the MDS has become an integral part of the curriculum of some Israeli medical schools and is currently being introduced into nursing schools, where it forms part of the advanced curriculum in geriatrics.

Professionals working in the geriatric field to whom the MDS has been introduced have responded positively, emphasizing the importance of a tool that allows assessment and planning based on a standardized database.

#### **GLOSSARY**

ADL .....	Activities of Daily Living
CLTCI .....	Community Long-Term Care Insurance
FP .....	For-Profit
HAH .....	Hospital-at-Home

HC .....	Home Care
HH .....	Home Hospitalization
HMO .....	Health Maintenance Organization
IADL .....	Instrumental Activities of Daily Living
LTC .....	Long-Term Care
MDS .....	Minimum Data Set
NFP .....	Not-for-Profit
NH .....	Nursing Home
NII .....	National Insurance Institute
PAC .....	Post-Acute Care
RAI .....	Resident Assessment Instrument
SNF .....	Skilled Nursing Facility
TAMI .....	Triangular Approach to MDS Implementation

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**THE IMPLEMENTATION OF A COMMON ASSESSMENT SYSTEM  
AND CARE MODEL IN ITALY**

**Roberto Bernabei, Marina Panfilo, and Giuseppe Panio**

**EXECUTIVE SUMMARY**

Before the mid-1990s, Italians relied upon acute care hospitals to solve a wide range of problems related to the assistance of the elderly. As a result, in 1992 the average length of stay in Italian internal medicine wards was about 18 days, mostly due to the elderly not being discharged.

In the early 1990s, the Italian National Health Service (NHS) underwent a series of reforms. One reform divided the nation into approximately 250 local Health Agencies, each further subdivided into districts; the Health Agencies' general directors (CEOs) received the mandate to adopt a "corporate mentality" even though the enterprise was state-owned. Another reform led to the introduction of Diagnosis-Related Groups (DRGs), which dramatically changed the approach to the long-term care of frail elderly patients.

The aging of Italy's population and the rising number of Health Agency clients, along with a new prospective payment system and the NHS's corporate philosophy, pushed the local Health Agency CEOs toward redesigning the long-term care system and shifting resources from the hospital to the community.

In this context, the Institute of Internal Medicine and Geriatrics of the Catholic University of Rome, a well-known research institution, demonstrated that community-based care could be improved by training personnel in multidimensional geriatric assessment and by integrating services via case management.

At the same time, Pfizer Italy was updating its mission, deciding to target local health authorities and Health Agency CEOs. A new partnership arose between Pfizer and Catholic University that allowed the pinpointing of the Health Agencies' primary needs and promoted a community care model of services based on case management and a second-generation assessment tool, the Resident Assessment Instrument-Home Care (RAI-HC). The Catholic University group was responsible for the scientific and educational leadership of the project, dubbed the Silver Network, over its whole duration. (The project has been going on since 1997.)

Thirty-two Health Agencies began to work according to the agreed model; to date, 25 (10 percent of the total number of Health Agencies) continue to do so.

The intervention produced a change in the relationships between professionals, who had been accustomed to working by themselves without sharing information, as well as a change in the flow of information among the professionals, making it more logical. A second outcome was a reduction in the number of admissions to acute care hospitals among clients followed by case management, thus reducing the costs of care.

In general, Health Agency CEOs and policymakers immediately understood that the RAI-HC/case management system was effective and could provide data useful for epidemiological, administrative, and management purposes. They were easily convinced by the evidence-based data produced by intervention research carried out using RAI-HC as the assessment tool. There were some difficulties, however. Because people working in geriatric care were, before the RAI-HC's introduction, almost

entirely ignorant of multidimensional assessment techniques, various professionals had a hard time accepting the rationale of the new system. Once the initial difficulties were overcome, however, the professionals responded extremely positively to the assessment tool and the case management system.

The future course of the RAI-HC in Italy has three aspects: legislative/regulatory, administrative, and research-related.

On the legislative/regulatory front, the regions of Italy will in the future have a tool to use for accrediting home care programs run either by the Health Agencies or by private cooperatives. On the administrative level, the Health Agencies can justify and standardize the costs of home care services through the use of an MDS-HC database now under development. That database will serve as the launch site for exploring the RAI-HC's research potential. As shown by experiences elsewhere, databases generated by comprehensive geriatric assessment instruments can provide valuable information about a population usually excluded from mainstream research.

RAI-HC is, beyond doubt, a good assessment tool. Nevertheless, nothing is sold without sellers. Pfizer's people did what the Italian representatives of *interRAI* and their coworkers could never have done: they went to the Health Agencies and directly promoted the product. Without their efforts, very few Health Agencies would currently be using the RAI-HC.

A general problem remains, however, regarding how to disseminate tools, procedures, and processes that can improve present policies and behaviors on such huge issues as frailty and long-term care. First of all, policies need to be evidence-based, and in this field evidence is very difficult to obtain. Even when the evidence is available, as is the case with the RAI-HC, a tool's success among potential users is not assured. Presenting this story of RAI-HC implementation in Italy is one way of addressing the problem.

## **BACKGROUND**

Italy has one of the world's fastest-growing elderly populations, and, as in all western countries, growth is most rapid among the oldest old. Curiously, however, in the early to mid-1990s, Italy ranked lowest among western nations in the number of residential beds for the elderly: about 22 beds per 1,000 people over 65. (No other western country had fewer than 60.) The numbers of elderly receiving professional care services at home were even lower, accounting for less than 1 percent of those over 65 years of age, with higher rates in a few northern regions (ISTAT 1997; Lopez 1987; Lori, Golini, and Cantalini 1995).

The low number of nursing home beds and the shortage of home care services were due both to the typical Italian family structure and to the widespread use of acute care hospitals for the care of the sick elderly. Italian families, whether because of choice or of lack of opportunities, traditionally take responsibility for the care of their elderly members, even when the elderly person is very frail. In southern Italy, this tradition is central to a culture that views care of the elderly as a natural responsibility of the family.

Moreover, prior to the mid-1990s, Italians relied upon acute care hospitals to solve a wide range of problems related to the assistance of elderly people. As a result, the length of stay in Italian internal medicine wards in 1992 averaged around 18 days, mostly due to the elderly not being discharged. This high use of inpatient beds (which in those years numbered 7 per 1,000 inhabitants) was not consistent throughout the country, however. There were marked differences between the north and the south. A study sponsored by the National Research Council in the late 1980s showed that in-hospital mortality was six times higher in hospitals located in the north than in hospitals in the south, even adjusting for disease and clinical severity. Southern Italian families (which tend to be larger, with more relatives available for elder care, and with a higher level of unemployment, so therefore also more available for caregiving) have more time and emotional resources to manage the death of a relative, and they often ask that a relative be discharged when the prognosis is terminal. In contrast, in the north, families often leave the management of a terminal patient and the subsequent death to the hospital.

Before the mid-1990s, the only state directives on the care of the elderly were those included in the so-called Progetto Obiettivo Anziani (Targeted Program on Aging), which invited all local health authorities to provide the elderly with nursing homes and home care programs supervised by a Geriatric Evaluation and Management Unit (GEMU). Not many authorities followed those suggestions.

In the early 1990s, the NHS underwent a series of reforms. One reform divided the nation into approximately 250 local Health Agencies, each further subdivided into districts; the Health Agencies' general directors (CEOs) received the mandate to adopt a "corporate mentality" even though the enterprise was state-owned. In the 1990s, the key word of the reform process was *aziendalizzazione*, which denoted the process of transforming local health care providers into private enterprises that, like private companies, would follow rules of corporate management and engage in competition. Another reform led to the introduction of something that dramatically changed the approach to frail elderly patients in need of long-term care: in 1993, hospital reimbursement shifted from a fee-for-service system to a prospective system based on the Diagnosis-Related Groups (DRGs).

The aging of the Italian population, the rising number of "clients" of the Health Agencies,<sup>1</sup> this new prospective payment system, and the corporate philosophy were the driving forces that pushed the CEOs of the local Health Agencies toward redesigning the long-term care system and shifting resources from the hospital to the community.

The Health Agencies and their CEOs immediately had to attempt to rectify the poor geriatric training of the professionals who were to be involved in this redesign of long-term care (LTC). At the end of the 1980s, medical schools (in particular, these schools' residency programs in geriatrics) were the only Italian institutions offering appropriate training in the management of geriatric patients and the care of the frail elderly. While these programs were able to provide good preparation in the use of geriatric assessment and drugs and in the treatment of syndromes related to the aging process, they were not ready to help design the new health care models needed to change the structure of the NHS.

Other schools training professionals who participate in the care of the elderly (e.g., nurses, rehabilitation therapists, social workers) were not prepared even to give the minimal training

provided by the medical schools. For example, the concepts of geriatric assessment accepted by the medical schools in the mid-1980s were not yet being taught in nursing schools ten years later.

At that time, only partial and “local” solutions for managing the care of the frail elderly were available, because there was no law indicating the direction of LTC or the practical terms for its reorganization. But no one was worried about this situation, and some probably preferred it, feeling that the vagueness of the situation allowed them a personal, “creative” approach in experimenting with new care models and strategies. This “individualistic” approach applied even to gigantic problems, such as the redesign of LTC. Some Health Agencies opened home care programs (some in cooperation with the local municipalities). Others opened nursing homes under the direction of general practitioners (GPs), while others hired geriatricians to run such facilities. Some Health Agencies created a GEMU with a GP as chief; still others put a pediatrician in place as chief; and yet others even chose a lawyer. No Health Agency, however, instituted anything that might properly be called a *network* of care.

In this context, the Institute of Internal Medicine and Geriatrics of the Catholic University of Rome, a well-known geriatrics research institution, sought to demonstrate that community-based care could be improved through the following two activities:

- Training Italian personnel involved in elder care in the use of a multidimensional geriatric assessment system that would serve as the core of the management of an elderly person’s care.
- Implementing a new model of community care based on the provision of integrated services to the frail elderly. This model, if deemed effective, would be proposed to other potential users.

The Catholic University research team performed a two-part test of its proposal in Rovereto, a town in northern Italy with a population of 35,000 (the size of a typical health district). The local Health Agency had considerable experience with community-based care, although it was not using a comprehensive multidimensional assessment tool and did not integrate its services with the social services delivered by the municipality. In 1995, the Ministry of Scientific Research provided funding for the research team to work with the Rovereto Health Agency and town government to accomplish the following:

- Provide a three-week course that would introduce all Rovereto professionals involved in elderly care at the home care level to an improved geriatric assessment system.
- Select from among the people attending this course two case managers who would implement a model of integrated home care in which a district GEMU would provide both medical/nursing and social care. As the operational arm of the GEMU, the case managers would not only be in charge of the multidimensional assessment required for the care plan but would also control the delivery of services to those cared for by the GEMU.
- Randomize the population of elderly under care in the home care programs managed by the Health Agency and by the municipality (about 200 clients) into two groups. One group would receive the traditional, fragmented home care, while the second would be cared for by the new case manager-centered GEMU.

The educational section of the program was based on the Resident Assessment Instrument (RAI) for nursing homes. Although this instrument was designed for nursing home residents, the research team felt that it, because of its comprehensiveness, would best acquaint personnel with geriatric assessment. Also, the care-planning facilitating tools embedded in the RAI (the Resident Assessment Protocols, or RAPs) were particularly useful in highlighting and summarizing problems that are common in the frail elderly (incontinence, pressure ulcers, cognitive and physical impairment, etc.).

The results of this project were impressive. The GEMU personnel in Rovereto—a total of 25 nurses, physical therapists, and social workers—easily understood the technique as well as the philosophy underlying it. The two nurses who became case managers perceived their new role as a professional advancement—a step above their traditional role as physicians’ assistants.

Furthermore, training in the RAI’s multidimensional approach to assessment provided the nurses with a method for identifying problems that was much better than the vague, not fully justified process used before. The study’s results, including the participating professionals’ satisfaction with this educational intervention, were published in a series of papers on gerontological education (Cipriani et al. 1995). Finally, the RAI system, with its comprehensiveness, triggering process, and RAP-based procedures for designing a care plan, promoted a team approach to care, unusual in such an individualistic country as Italy.

After appointing the case managers, the research team proceeded to randomize clients into two groups of 100 each. The case managers and the GEMU followed one group; the other—the controls—continued to receive the traditional kind of home care. The research team chose an existing comprehensive, multidimensional assessment form—one developed to determine eligibility for long-term care services in British Columbia, Canada—as the basis for assessment of all participants during the baseline and one-year evaluations.

The study revealed that, after one year, clients being served by the case-management approach showed greater improvement than the controls in physical and cognitive function and mood status and were admitted to institutions (acute care hospitals or nursing homes) much less frequently than their counterparts.

The integrated care model also achieved savings of approximately US\$1,000 per year per client. Keeping in mind that this was the amount of money given each year by the NHS to each Health Agency for the comprehensive health care needs of each citizen, this saving was significant (Bernabei, Landi, et al. 1998).

This study generated two important pieces of information useful for Health Agencies throughout Italy. First, the personnel who deliver care to the elderly can be trained to understand and use geriatrics “skills”—that is, the multidimensional assessment and the team approach. Second, a new, validated model of integrated care—the case management approach—was available for organizing LTC for elderly people in the community.

## OUTREACH

In 1997, the interRAI group developed a new instrument, the RAI-Home Care (RAI-HC) (Mor et al. 1997; Morris, Fries, Bernabei et al. 1996; Morris et al. 1997; Phillips et al. 1997). One of the authors of the present paper, Roberto Bernabei, served on the RAI-HC overview committee and was the leader of the Catholic University geriatric research team. The availability of the new instrument, along with the positive results of the Rovereto study, allowed the Catholic University research team to ask the Italian Research Council (Consiglio Nazionale delle Ricerche, or CNR) for an extension of their research project into the use of case management, now to include the use of the RAI-HC. The CNR funded this proposal with a dedicated grant in 1997.

The research experimentation initially proceeded slowly, due to scant resources (the total amount of the grants for the Rovereto study and from the CNR did not exceed US\$100,000) and the lack of any political mandate to implement the new system in any other Health Agency. Even in Rovereto, the new system faced difficulty: a new political coalition took over the government of the municipality and immediately decided to stop the case management–based home care program and return to the previous model. The old custom of finding local solutions for elderly care, even against the evidence, was clearly winning in Rovereto and around the country.

The change in this situation came from an unforeseen source, and the consequences were far-reaching. At the time, Pfizer Italy was updating its mission in the pharmaceutical industry, which had traditionally focused on research and development and the marketing of drugs. Pfizer had always been concerned with the community and the general practitioner, and the company had been the first to use the logic of customer care as the basis for a partnership with, rather than a sponsorship of, patients. Against this background, Pfizer decided to create a department devoted to the implementation of innovative projects in health care. These projects would alleviate both the financial and the organizational burdens of new models of care and would introduce technology to support the integration of care. Traditionally, the pharmaceutical industry's main customers had been physicians, but in the new health care environment they would not remain the only decision makers, because access to health care services would depend more and more on economics. For this reason, Pfizer decided to find ways to start targeting local health care authorities and Health Agency CEOs.

The company thus initiated an intervention to support an improvement of services delivered at the community level, using the logic of quality, effectiveness, and efficacy that is typical in managed care. For this intervention, Pfizer chose the services directed at the elderly population—specifically, home care services—because this segment of the population was increasing at a very fast rate, making Italy the “oldest” nation in the world. As a first step, Pfizer Italy, in collaboration with social researchers from the Center for Social Studies and Policies (Centro Studi Investimento Sociale, or CENSIS) and epidemiologists from the University of Rome-Tor Vergata, analyzed the realities of home care in Italy. The results were surprising. Only 15 percent of those receiving a service in the community were satisfied with it. Only 118 out of 228 Health Agencies had started experimental home

care programs, and most of these were not integrated with social services (as had been seen in Rovereto). Further, medical/nursing and social service home care programs were scarce, and there were no common standards to determine eligibility, oversee management, or evaluate outcomes in the care of elderly patients.

In addition, there had been a decline in the number of inappropriate hospital admissions and a dramatic reduction in lengths of stay, both consequences of the introduction of the prospective payment system based on the DRGs. The effects of the prospective payment system on elderly care were particularly pronounced because there had been no increase in rehabilitation, post-acute, and home care services needed to guarantee continuity of care after hospital discharge, even as hospitals could no longer provide a buffer for the paucity of the long-term and community services for the elderly. Moreover, such services as did exist were not satisfactory, either qualitatively or quantitatively. The implementation of the DRG-based prospective payment system had, in fact, worsened the inadequacy of the entire elderly care system.

The Pfizer/CENSIS/Tor Vergata analysis then proceeded to map the Geriatric Evaluation and Management Units in Italy. The goal was to identify those Health Agencies that were in particular need of integrated home care services but lacked the scientific, technical, and educational support to implement such programs. Marina Panfilo, Pfizer's national key account manager and one of the authors of the present paper, contacted many research groups to find existing initiatives that could provide models for the needed changes. Based on its successful experience on the Rovereto study, the Catholic University group was chosen to be Pfizer's partner in this initiative.

The partnership between Pfizer and Catholic University pinpointed the primary needs of the Health Agencies: a model for community care services and an assessment tool. The model was the case management approach already tested in Rovereto. The assessment tool would be the RAI-HC, because it could provide a complete and multidimensional assessment for the identification of patients' problems and serve as the basis for creating individualized care plans. This validated tool was already available, but it was necessary to translate it, to create data-entry software to store the information, and to provide a teaching program on its use. Pfizer obtained an interRAI license to use the RAI-HC in Italy and financed its translation, computerization, and implementation. The implementation was made possible through training courses given by the Catholic University team and, as explained below, through Pfizer's network of people. By mutual agreement between Pfizer and the Catholic University, this tool would also be used to assess resources utilization, so that the cost-effectiveness of the intervention could be evaluated (Morris et al. 1996).

The Catholic University group was responsible for the scientific and educational leadership of the project (by that time dubbed the Silver Network) for the entire duration of the project, which has been going on since 1997 (Landi, Lattanzio, et al. 1997). The university developed and provided a standardized program for a six-day training course (Landi et al. 1996). The program was organized as follows:

- *First day.* Main theories on aging; demographic and epidemiological issues; multidimensional assessment and main assessment tools; the RAI-HC tool; the trigger system; item-by-item analysis

- of RAI-HC sections AA through H; practical training on the sections evaluating physical impairment, cognitive impairment, and psycho-social status.
- *Second day.* Item-by-item analysis of RAI-HC sections H through Q; practical training on the entire assessment form; introduction to the Client Assessment Protocols (CAPs).
  - *Third day.* Presentation and in-depth discussion of CAPs related to functional performance: activities of daily living (ADLs) rehabilitation potential, instrumental activities of daily living (IADLs), health promotion, institutional risk; discussion of CAPs related to sensory performance and mental health: communication disorders, visual function, alcohol dependence and hazardous drinking, cognition, behavior, depression and anxiety, elder abuse, social function.
  - *Fourth day.* Presentation and in-depth discussion of CAPs related to health problems and syndromes: cardio-respiratory, dehydration, falls, nutrition, oral health, pain, pressure ulcers, skin and foot conditions; discussion of CAPs related to service oversight: adherence, brittle support system, medication management, palliative care, preventive health care measures, immunization and screening, psychotropic drugs, reduction of formal services, environmental assessment; discussion of CAPs related to continence: bowel management, urinary incontinence, indwelling catheters.
  - *Fifth day.* Screening of a videotape of a simulated case; practical training for small groups (maximum five students), with a tutor, using a real case of a client in home care and performed at the client's home; after the triggering of the CAPs, the students prepare the specific care plan for that client.
  - *Sixth day.* Presentation to the other groups of the practical training cases, from assessment through care planning; discussion with the rest of the class, the tutors, and the teachers. (The training course's last two days give students the opportunity to evaluate an actual case in a hands-on way and to participate in discussion of about three other cases.)

This outline is reported in full because it explains how it has been possible to effectively communicate the core elements of the geriatric assessment tool to those involved in providing care to the elderly. The Catholic University team considered the RAI-HC instruction manual an outstanding geriatric-gerontological textbook because of its explanation of the CAPs (analogous to the RAPs in the nursing home RAI) and because it provides the capability to identify a problem using just the triggers embedded in the assessment form. This intensive course gives personnel a level of knowledge that they could not achieve so rapidly and efficiently in any other way (Morris et al. 1996).

With Pfizer's support, the team drew up a plan to inspire Italian Health Agencies to train their professionals in the use of the RAI-HC and to implement it as part of an entirely new home care service program that would include case management. Pfizer's ability to communicate this new model to Health Agency decision makers was the crucial element in this process. A group of 15 persons from Pfizer, specifically trained in public health and health economics, had the mission of creating the best possible environment for its new-drugs market and of disseminating a disease-management culture in which drugs would play a significant role. The Pfizer group contacted Health Agency CEOs and tried



to create a bridge between specialists in geriatrics, general practitioners, nurses, social workers, and health care managers. This bridge rested on two pillars: case management and the RAI-HC.

To be a suitable candidate for this plan, a Health Agency had to have—or had to be willing to put in place—a home care program with at least 15 nurses, thus providing a reasonable number of patients and the certainty that the Health Agency would be willing to redesign its LTC services. Pfizer’s national key account manager (KAM) contacted those CEOs who expressed a willingness and ability to implement the new service, and a formal deal was worked out. Pfizer, using the Catholic University team, committed itself to training the personnel who would be involved in the Health Agency’s home care program and to providing all the participants in the course with the RAI-HC instruction manual and the software to store the information; a new section on costs was added to the tool as well. In turn, Pfizer asked the Health Agency to commit itself to organizing its home care service according to the case management approach, using the training course as the occasion to select and train case managers. Finally, Pfizer and the Health Agency had to coordinate their work with local GPs, who provide the bulk of medical care to the elderly.

This last part of the deal was the most problematic because it touched on the GPs’ role and prerogatives. In Italy as in many other countries, GPs are the cornerstone of the National Health Service (NHS). According to Italian law, the GP is solely responsible for the citizen’s health, and in an individualistic country like Italy, he or she doesn’t forget it! Italy’s 55,000 registered GPs represent what is probably the country’s single most powerful professional guild. Understandably, GPs do not easily accept what they consider intrusions into their domain.

The most recent contract between the GPs and the NHS specifies that an extra amount of money is to be paid for what are called “planned home visits” to elderly patients. According to many GPs, this additional remuneration allows them to meet the needs of the homebound elderly. This clause brought the GPs into direct conflict with the Health Agencies over the new approach being pushed by the Pfizer-Catholic University partnership. The new system allowed case managers to take care of their patients without (apparently) the direct involvement of the GP, and many general practitioners believed this to constitute a clear threat to their relationship with their patients.

The Catholic University team leader, Pfizer’s national KAM, and the local KAM therefore met multiple times with the local GPs in each Health Agency to explain how the Silver Network would, in fact, be very useful to them. The Pfizer-Catholic University representatives emphasized the following points:

- The case management approach, through careful assessment and the provision of integrated services, is designed to address problems of frail patients that are otherwise left unsolved.
- Existing data suggested that, in similar communities, the new system was effective in improving health outcomes.
- The case manager’s authority would be subordinate to the GP’s regarding the patient’s clinical and, especially, pharmacological management.

These conversations were only successful, however, in cases where the Health Agency CEOs were

**TABLE 1. CHANGES IN THE LTC STRUCTURE BEFORE AND AFTER RAI-HC IMPLEMENTATION**

Services	Before	After
Organization	Hierarchical	Teamwork
Aims	Left to the individual	Predefined, agreed, shared
Intervention	Uncoordinated, sectorial	Coordinated, targeted
Evaluation	Subjective, not based on evidence	Objective, systematic, based on fulfillment of aims

**TABLE 2. CHANGES IN THE ROLE OF PARTICIPANTS IN LTC AFTER RAI-HC IMPLEMENTATION**

	Before	After
Client involvement	None	Active involvement by client and family
Staff approach	Individual	Multidisciplinary
Cultural exchange	Poor, infrequent	Constructive, frequent
Information flow	Physician ↓ Nurse/Rehabilitation therapist ↓ Social Worker ↓ Client	

very committed to the effort and used all the leverage they had to persuade the reluctant GPs, by renegotiating the number of funded annual planned visits, for example, or by promising to pay any GP the money budgeted for one planned visit in exchange for that GP's participation in the GEMU meeting at which the care plan of his or her patients was discussed.

In the end, the team contacted 80 Health Agency CEOs, 35 of whom agreed to initiate a home care service program—or transform an existing home care program—according to the case management model, using RAI-HC as the assessment system. These 80 Health Agencies were the only ones with home care programs large enough to be worth reorganizing. The approximately 170 other Health Agencies totally lacked such programs or provided home care services to very few patients. To

date, 32 Health Agencies have begun implementing the new model, of which 25 are still in operation. We estimate that, at present, about 10 percent of Italian Health Agencies are using the same model for caring for the frail elderly—a model that is based on case management and that uses the RAI-HC.

## **OUTCOMES**

The potential effects of the implementation of the RAI-HC system on care planning are summarized in tables 1 and 2; these outcomes were initially conceptualized by one of the case managers trained by the Catholic University team, who worked full-time in the Vittorio Veneto Health Agency (Landi, Onder, Russo, et al. 2001).

The tables show the methodological revolution that follows the implementation of a comprehensive, care planning-oriented tool such as the RAI-HC. This revolution is similar in concept to the modifications seen in industry when a new technology is introduced and the traditional process of production is changed. It is not by chance that some have defined comprehensive geriatric assessment (CGA) as the “technology” of geriatrics (Rubenstein, Wieland, and Bernabei 1995). Because it is more complex than traditional tools, and probably also because, in Italy, the assessment instrument was being used by people who had no previous knowledge of this kind of technology, the RAI-HC produced true innovation.

The first set of outcomes concerned the relationships between professionals in the field of elderly care. Before the RAI-HC’s implementation, these professionals had been accustomed to working by themselves, without sharing information. Now they worked in teams. The flow of information among professionals also changed, becoming more logical. The implementation also altered the role of the nurse. The new case manager who prepared the two tables reproduced here was taking on a role previously unknown among Italian nurses: that of following a screening and diagnostic process to identify the causes of the problems reported by the client.

Until the introduction of the RAI-HC, too much was left to the physician, while other health care professionals played only a marginal role, at most that of executing the physician’s orders. Today, the case managers are able, for instance, to precisely detect nutritional problems in their clients because the assessment lets them know if a client has lost more than 5 percent of body weight over the last 30 days (item L1a=1, which triggers the CAP on nutrition). Further, the nutrition CAP itself helps them rule out causal hypotheses of, say, multiple drug regimen, or terminal illness, or depression. Once this diagnostic process has been accomplished, the case manager can interact with the physician to discuss and together develop an appropriate care plan that can include both medical and social interventions. Before the introduction of the RAI-HC, all the nurse could do was to relate a subjective impression of a weight loss, without any validation or standardization. As a consequence, the physician was less likely to take the communication into serious consideration and might just order some examination or diet that the nurse would arrange without any involvement in the decision-making process.

The second set of outcomes of the RAI-HC/case management system's implementation has to do with the client. Two papers describe the client-related outcomes: one describes what occurred in Rovereto, which was the first Health Agency to implement the new system (Landi, Gambassi, et al. 1999); the other documents the activities of the four Health Agencies that were next to initiate home care programs based on this approach (Landi, Onder, Russo, et al. 2001). In all these experiences, admissions to acute care hospitals fell for clients followed by case management. In addition, when clients were admitted to the hospital, they were discharged more quickly. All this was accomplished without a change in overall mortality. When clients were able to stay at home, there was a substantial improvement in their quality of life.

Another outcome relates not just to the reduction in hospitalization rates and lengths of stay but to the associated savings realized by the Health Agencies. One of the authors of this paper, Giuseppe Panio, was general director of the Health Agency of Venosa (in the south of Italy) at the time of the home care implementation there. As CEO, he had seen the financial problems caused when too many older citizens belonging to his Health Agency were admitted to hospitals of other Health Agencies. His agency was responsible for paying for these admissions, and the data generated by the intervention convinced him that the case management approach could reduce these costs. He decided to implement a Silver Network site. After a single year, hospital admissions dropped from 15 to 5 percent, with corresponding money savings.

The Venosa experience is common to all the Health Agencies: hospital admission is very costly, and reducing costs related to hospital admissions is necessary to contain the budget. The dramatic worldwide increase in the size of the elderly population along with the concurrent pressure for cost containment efforts in the health sector necessitate a shift in resources from the hospital to the community, where costs are lower and problems related to frailty are also better managed. In Italy, this change was coincident with a reduction in the number of acute hospital beds in the country (now 6 per 1,000 population) and an increase in the number of people in home care. The Silver Network helps by producing original data that support Health Agency CEOs in making choices that permit this shift in resources.

## **SUSTAINABILITY**

The future course of the RAI-HC in Italy has three aspects: legislative/regulatory, administrative, and research-related.

On the legislative/regulatory front, the regions of Italy will in the future have a tool to use for accrediting home care programs run either by the Health Agencies or by private cooperatives (the accreditation process is the regions' responsibility).

The RAI-HC system has been tested in one of the districts of the Health Agency of Bergamo, a medium-size, wealthy city in the north of Italy that is participating in the Silver Network. The study

performed in Bergamo compared the results of the RAI-HC assessment (and the care plan and overall management that followed) with those obtained by other well-established tools, including the Barthel and the Lawton scales, which measure physical function; the Mini-Mental State Examination, which measures cognitive function; and the Geriatric Depression Scale, which measures mood status (Landi et al. 2000).

The comparison was made possible because another district of the same Health Agency had a case management-based home care program, but one that used these “traditional” scales. At the beginning of the study, all the clients involved had similar clinical and functional characteristics, but one year later, the clients assessed with the RAI-HC had higher levels of physical and cognitive functioning and had been hospitalized less frequently. This is probably due to the increased confidence of personnel using the RAI-HC, which better enables them to detect and treat clients’ problems. Further, care plans triggered by the RAI-HC are more precise in targeting the problems of individual clients. This more accurate care results, in turn, in clients being able to delay or even avoid hospitalization. The paper presenting these results (Landi, Onder, Tua, et al. 2001) provided partial evidence regarding some of the characteristics that a home care program should have to perform at the best possible level. An evidence-based home care program should use RAI-HC as its assessment tool, and the published data now available support the region in requiring that the RAI-HC be implemented as a requisite for accreditation.

On the administrative level, the Health Agencies must justify and standardize the costs of home care services. This is problematic because these services are increasingly often provided by private cooperatives of nurses and physical therapists, which are reimbursed by the Health Agency. Under a grant from the Italian Ministry of Health, a group from the Istituto Nazionale Ricovero e Cura Anziani (INRCA) and the Catholic University’s geriatric research team was able to validate the Resource Utilization Group, Version III (RUG-III), case-mix system in the context of the Italian NHS. This system measures the burden posed by the individual patient, in terms of minutes of care, on the nursing home and its staff and makes it possible to obtain the case-mix of a facility by averaging the complexity of the needs of all the patients in that facility. The RAI-HC includes the Home-care Utilization Groups (HUGs) algorithm, which is similar to RUG-III and allows the same kind of case-mix determination to be made about the clients of a home care program. We expect that, in the future, Health Agency administrators will use this case-mix measure to reimburse those who provide home care services. In addition, the HUGs can be used to define clients’ characteristics in terms of resource consumption. By using either the HUGs or the scales embedded in RAI-HC it is also possible to “classify” the client and to make the delivery of services more rational with regard to personnel needed and procedures used. It is clear that this can only occur, however, if databases are created that permit analysis of the information collected with the multidimensional assessment tool in multiple settings throughout Italy.

Such databases would serve as the launch site for exploring the research potential of the RAI-HC. As experience elsewhere has shown, databases generated by comprehensive geriatric assessment

instruments can provide valuable information on a population usually excluded from mainstream research. It is, for example, useful to recall the experience of the Systematic Assessment of Geriatric drug use via Epidemiology (SAGE). SAGE, which was assembled by Roberto Bernabei, working with Vincent Mor of Brown University, contains the nearly two million assessments performed over a five-year period in nursing homes in five U.S. states (Kansas, Maine, Mississippi, New York, and South Dakota), encompassing a total of nearly 750,000 residents (Landi, Onder, Tua, et al. 2001). The database also contains data from the U.S. Centers for Medicare & Medicaid Services (Medicare part B) on hospital admission and data from the OSCAR (Online Survey Certification and Reporting) survey on facilities' characteristics. This data set has made it possible to study a population with a mean age of 83 years—a group that is seldom included in traditional studies. Evidence-based medicine is, in fact, usually based on randomized clinical trials that exclude persons older than 75 years, either for logistical reasons or because of concerns about the presence of potential confounders due to comorbidity. Research conducted using the SAGE database revealed, for example, that pain suffered by nursing home residents with cancer often went untreated (Bernabei, Gambassi, et al. 1998), that ACE-inhibitors are more effective than digoxin in treating heart failure in people older than 80 (Gambassi et al. 2000), and that the first drug shown to be effective in the treatment of Alzheimer's disease, tacrine, was often incorrectly prescribed (Gifford et al. 1999). While the nursing home residents are the "extremes," the clients of a home care program are closer to the general elderly population. To gain information on this population, the Catholic University geriatric research team, thanks to a grant from the Ministry of Health, is collecting all the assessments performed at the sites participating in the Silver Network.

The first information forthcoming from this database will address measures of the quality of care delivered, using the indicators contained in the RAI-HC (use of psychotropic drugs, prevalence of incontinence, prevalence of mood disturbances, prevalence of pain, and so on). Afterward, it will be possible to start a continuing education effort for the professionals of the Silver Network home care program—one based on the actual problems detected by analyzing the data they provide. For example, if a given home care program shows a prevalence of incontinence much higher than that of other programs with similar case-mixes, and if the comparative data are presented to the people working in that program, it is likely that they will be better motivated to learn how to improve the management of incontinence.

It should be stressed that the database and continuing education effort just described are only possible when comparable data are obtained from the multiple programs, centers, and agencies providing integrated home care in different Health Agencies. This, in turn, requires that all work be performed in a standardized fashion, using the same assessment tool.

Following the same logic, it becomes possible to envision comparisons of very large scope, conducted at the European level. The European Commission's Fifth Framework Programme, "Quality of Life and Management of Living Resources," Key Action 6, "The Ageing Population and Disabilities," has just funded (2001–03) a 1.3 million euro grant coordinated by Roberto Bernabei and involving 11 countries (the Czech Republic, Denmark, Finland, France, Germany, Iceland, Italy, the

Netherlands, Norway, Sweden, and the United Kingdom). The project, which goes by the acronym AD HOC (AgeD in HOme Care), aims to identify and propose a model of home care for the elderly through the analysis of the structural and organizational characteristics of multiple nations' home care services and the clinical and functional characteristics of their clients. The identification of the factors that can be correlated with positive patient outcomes at one year will contribute to the design of the first evidence-based home care service model. The project also aims to achieve several intermediate objectives:

- Description and comparison of the characteristics of patients in each European home care service
- Assessment of patient outcomes (changes in physical function, cognitive status, mood, quality-adjusted life years, survival) in each European home care service over one year
- Description and comparison of both structural and organizational characteristics of each European home care service
- Evaluation of resources (hospital, institutional, and community care) utilized by patients in each service
- Identification, at both the patient and system levels, of the independent predictor of positive functional outcomes at one year

The AD HOC Project requires a considerable organizational and data-collecting effort—an effort that is made possible by the availability of a common assessment tool, the RAI-HC.

Finally, the Italian Society of Gerontology and Geriatrics has decided to support the adoption of the MDS family of instruments. This formal sponsorship has produced an agreement with the Association of Italian Directors of Nursing Homes (ANSDIPP) and Pfizer, Inc., which holds the RAI 2.0 license in Italy, to implement RAI 2.0 in 40 nursing homes throughout Italy. More than 500 nursing homes are members of the ANSDIPP, and the implementation in 40 nursing homes is an experiment to understand whether RAI 2.0 would be the appropriate common assessment tool for all the nursing homes that are members of the association. In the summer of 2002, the Ministry of Health, together with Pfizer, funded the construction of a database based on the RAI instruments for monitoring the quality of care for the elderly in acute and long-term care settings. Use of the RAI instruments in Italy will increase as additional ANSDIPP nursing homes participate, as the number of Silver Network home care agencies expands, and as the acute sector, including the Gruppo Italiano di Farmacoepidemiologia nell' Anziano (GIFA), which represents more than 50 internal medicine and geriatric wards located throughout the country, move into the RAI fold.

## **CONCLUDING OBSERVATIONS**

The use of RAI-HC generated a major difficulty, mostly due to the almost total ignorance of the multidimensional assessment technique by the people working in geriatric care. Various professionals had a hard time accepting the rationale of such an assessment tool and system. The authors of this paper usually opened Silver Network preliminary training courses by asking if anyone in the audience

was knowledgeable about the activities of daily living, which are the cornerstone of geriatric care. Many times, no one in the audience was able to respond positively. It is thus understandable that it was not easy for this new instrument or its cultural underpinnings to be easily accepted and disseminated. The instrument's complexity and the administrative time it consumes also motivated initial resistance to the implementation.

Once the initial difficulties were overcome, however, the professionals responded extremely positively to the new assessment tool and system. This enthusiasm helped personnel endure the long training courses and to complete the very long field assessments. (The necessity of a long training program and the time required for the assessments are the very factors that could hamper the use of this tool in countries such as the United States.)

Italian professionals have come to understand that the RAI-HC's usefulness does not stop at the assessment level and that, in fact, the assessment tool allows

- Nurses to accurately diagnose the problems to be addressed within the complex clinical status of a frail elderly person, offering a substantial improvement in the management of the client and easing the global burden for the service.
- Nurses to upgrade their role. The assessment tool gives nurses a much greater understanding of clients' problems, enabling them to go beyond merely executing physicians' orders and to become active players in planning clients' care.

General practitioners' acceptance of the RAI-HC system was facilitated by their understanding that the nurse's role, though upgraded, would still be subordinate to the physician's. Formal documents from the Health Agencies were not sufficiently convincing, and so it was necessary to hold many meetings with GPs during which they could discuss their reticence regarding case management and the RAI-HC. This direct communication, as well as the CEOs' willingness to participate, fostered the GPs' acceptance.

Italian geriatricians' persistent refusal of the RAI system was probably due to their suspicion of the agreement between the Catholic University geriatric team and Pfizer. The geriatricians, and probably many other health care policymakers and providers, as well, felt that there may have been "dirty dealing" between the two, and that only the Catholic University team stood to gain from the arrangement. Aside from this, however, it remains the case that Italian geriatricians' acceptance of any common, standardized assessment system would be extraordinary. As we have said, the Italian mentality is very individualistic, and trained specialists use their own judgment and follow their personal intuition, often excluding what might be objectively desirable. (And, to be frank, the geriatrics field worldwide seems to be infected with this "individualistic virus.")

At the level of the CEOs of the Health Agencies and of policymakers in general, however, everything ran smoothly. The CEOs immediately understood that the RAI-HC was an effective system and could provide data useful for epidemiological, administrative, and management purposes. They were easily convinced by the data produced by the intervention research done with the RAI. Interestingly, they behaved as the MDs should behave, quickly coming to rely on a tool that produces



evidence-based data. The RAI and case management system's full potential has not yet been exploited, however, because the construction of a database proceeds slowly, and CEOs are not yet able to envision how it might be used. Local policies have therefore not changed since the implementation of RAI-HC and the associated data collection. On this score, the Catholic University research team made a mistake by failing to supervise the local users' teams in the provision of accurate data collection within the specified reporting times.

The RAI-HC is, beyond doubt, a good assessment tool, and we believe that its value, as compared with older, more traditional assessments is equivalent, say, to the value of a CT scan over the traditional x-ray. Moreover, not only does it produce a much higher "image resolution" and much more sensitive and specific diagnosis, but it also reduces costs. Nevertheless, nothing is sold without sellers. The support of Pfizer, which provided a network that "sold" the RAI-HC, has been essential to the assessment tool's success in Italy. Pfizer's KAMs did what the Italian representatives of *interRAI* and their coworkers could never have done: they went to the Health Agencies and directly promoted the product. Without their efforts, only three or four Health Agencies would currently be using the RAI-HC, and then only as an experimental tool.

Still, the Italian system of elderly care faces a critical paradox: even though there is a great and widespread need for instruments such as the RAI-HC and the other RAI tools, implementation is so far much lower than expected and has encountered considerable resistance. Reasons for this resistance can be found in Italian care providers' tradition of individualism, in the autonomy of each region and the lack of a centralized mandate for RAI utilization, and in the suspicion provoked by the agreement between the Catholic University research team and Pfizer.

A general problem thus remains regarding how to disseminate tools, procedures, and processes that can improve present policies and behaviors on such huge issues as frailty and long-term care. First of all, policies need to be evidence-based, and in this field evidence is very difficult to obtain. Even when the evidence is available, as is the case with the RAI-HC, a tool's success among potential users is not assured. We believe that the creation of the database on elderly quality of care funded by the Italian Ministry of Health will help in promoting the RAI instruments' diffusion. In addition, this presentation of the story of RAI-HC implementation in Italy is one way of addressing the problem.

## NOTES

- 1 In 1993, the number of Italians aged 64 years and older exceeded those under 15 for the first time (16 percent 64 years and older versus 15.2 percent from 0 to 14 years of age).

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## **EXECUTIVE SUMMARY**

Japan's rapidly aging population has led to a growing demand for long-term care (LTC) and produced huge increases in the use of hospital beds for LTC. In the early 1990s, the Ministry of Health and Welfare became interested in using the Resource Utilization Group, Version III (RUG-III) for case mix-based reimbursement in geriatric hospitals because officials feared that the flat, per diem rate for reimbursement, only recently introduced, would lead to hospitals' selecting cases requiring only light care. The government funded several RUG-III validation projects, which attained the same positive results as had those conducted in the United States, but it did not mandate LTC facilities' use of RUG-III because of providers' opposition and because the project revealed that LTC facility staff did not have enough expertise in undertaking comprehensive assessments. Consequently, interest shifted away from case mix-based payment toward the care planning potential of the Resident Assessment Instrument (RAI).

In the mid-1990s, legislators began seriously discussing the need for a new public LTC insurance (LTCI). As its design took shape, it became clear that two instruments would be needed: one for determining eligibility and another for drawing up care planning. The former would require an assessment form and an eligibility algorithm, but RUG-III appeared to be too complicated and too medically oriented for this purpose and the fact that it was protected by copyright raised difficulties. The latter required a home care version of the RAI. Thus, when *interRAI* started developing the RAI-HC, the Japanese government gave large grants for pilot programs testing its reliability and validity. The RAI-HC manual was first published in Japan in 1996. Although professional organizations subsequently developed and promoted their own instruments, the RAI-HC became the most popular of the five instruments recommended by the government after LTCI was implemented on April 1, 2000.

The RAI introduced the concept of care planning based on comprehensive assessments to Japan. Since use of these instruments is not mandated, however, it remains unclear whether they are actually being used appropriately. Most care managers are too inexperienced and too busy with billing and other administrative responsibilities, and even those using the RAI or RAI-HC are not all assessing on a regular basis, as prescribed, or exploiting the assessment protocols' full potential by integrating the results into their care plans. The vast majority of local governments lack the infrastructure to audit the assessment forms and care plans, and even the few municipalities that have started monitoring find their task complicated by the different assessment forms and care planning methodologies used by different providers. On the positive side, however, the very fact that the use of RAIs is optional has led to efforts to develop user-friendly manuals and software and to organize seminars to promote their use at the grassroots level.

## **BACKGROUND**

Japan has a population of 125 million crowded into 377,435 square kilometers (143,619 sq. mi.) of land, of which two-thirds is too mountainous to be habitable. The scope of the economy is second only

to that of the United States, with per capita income among the highest in the world. The health indices of infant mortality rate and life expectancy at birth are among the world's best (Ikegami and Campbell 1999). The country's population, however, is rapidly aging: the proportion of those 65 and over stood at 7 percent in 1970, was 16 percent in 2000, and is expected to reach 28 percent in 2025 (Campbell and Ikegami 2000).

Health care in Japan is financed by universal social insurance: two-thirds of the population is covered by an employment-based plan; the remaining one-third (nonemployees and pensioners) by a community-based plan. People do not have any choice between plans: each must enroll in the plan offered by his or her employer or by the municipality. Physicians and other providers are paid according to a fee schedule set by the government. Although payment is on a fee-for-service basis, costs have been contained by tightly controlling fees. According to the Organisation for Economic Co-operation and Development (OECD 2001), Japan's health expenditures, although they have recently increased because of the economic depression, still represented only 7.3 percent of gross domestic product in 1998. About 80 percent of Japanese hospitals are in the private sector; most of these are owned by physicians. Large medical centers, however, tend to be in the public sector because they receive subsidies to offset the deficits that result from providing high-tech services whose costs exceed the fee schedule's reimbursements. The private sector tends to focus on ambulatory care and long-term care (LTC), for which the fees tend to cover the costs. This is one reason hospitals have come to dominate LTC in Japan, with many hospitals becoming de facto nursing homes.<sup>1</sup>

In contrast to the entrepreneurial health sector, social services were, before implementation of public LTC insurance (LTCI), provided directly by the municipalities or through special social welfare bodies that they tightly controlled, and their growth was constrained by the government's budget. Services, including admission to nursing homes, were provided at the discretion of the municipal welfare office and subject to a means test. Although government funding expanded greatly from 1990 on, there continued to be wide geographical inequities, and citizens often had to fight bureaucratic rigidity to obtain services.

The rapidly aging society, the inappropriate use of hospital beds, and the problems associated with providing services through the social welfare system were the key factors that led to the LTCI law's enactment in December 1997 and its implementation in April 2000. The municipalities are the insurers, though there is a pooling mechanism at the national level to compensate for the differences in their demographic and income structure. LTCI benefits include institutional care, respite care, day care, home help, visiting nurses, loans of equipment (e.g., wheelchairs), and so on. The specific benefits that an individual is entitled to receive depend on his or her eligibility level. There are six eligibility levels, based on an 85-item assessment form and determined by a computer algorithm. An expert committee in each municipality is responsible for finalizing the eligibility determination (either approving the determination or changing the level, which occurs about 20 percent of the time). The 85 items on the assessment form evaluate functional and cognitive performance and the amount of support provided.<sup>2</sup> Unlike the former social welfare system, the LTCI system does not take into

account either the applicant's income or the amount of informal support that is available to him or her. For those in community care, benefits range from US\$500 to US\$3,000 per month. For those in institutional care, the insurance covers virtually all charges except meals. Once the eligibility level is determined, an individual can go to any provider and spend up to the amount to which he or she is entitled, subject to a 10 percent copayment. Providers employ care managers to draw up care plans, coordinate services, and do the billing for their clients.<sup>3</sup>

Over its first year of implementation, LTCI has generally been a success; there have been no major delays in eligibility assessment or delivery of community services to those in need, and expenditures have been less than budgeted. This is not to say, however, that there have been no problems. Some have criticized the process for determining eligibility for flaws in the algorithms, for not reflecting the amount of care required for those with cognitive problems living in the community, and for the uneven skills of those performing the eligibility assessments. Critics have also noted that care managers have too little time for care planning because they have to complete so many administrative and billing forms, and that too little attention has been paid to monitoring the quality of the care plans or the services provided (Ikegami 2001). Nevertheless, the LTCI system is an improvement over the ad hoc and inefficient allocation of services that existed before.

#### **RUG-III AND THE RAI'S INTRODUCTION**

The introduction of the Resident Assessment Instrument (RAI) in Japan has occurred in two overlapping but independent phases: the implementation of the Resource Utilization Group, Version III (RUG-III) system of case mix-based payment in LTC facilities, and of the RAI as a care planning instrument.

The case-mix phase started in 1991. The previous year, the Japanese government had introduced a flat, per diem rate for geriatric hospitals to correct abuses (overuse of medications, unnecessary lab tests) that had occurred under the fee-for-service payment system. Some feared, however, that the flat rate would lead to the selective admission of light-care cases.<sup>4</sup> Consequently, the government found the notion of case mix-based payment very attractive and made generous funding available for three research projects aimed at validating the RUG-III system:

1. A 1991-92 project involving 871 patients in four geriatric hospitals, one health facility for the elderly (a new type of intermediate care facility introduced in 1986), and three nursing homes controlled by the municipal social welfare office. The statistical variance explanation of the wage-weighted care time was 44 percent (Ikegami et al. 1994).
2. A 1992-95 project involving 1,255 patients in eight hospitals, four health facilities for the elderly, and three nursing homes. The variance explanation was 65 percent (Takagi 1995).
3. A 1993-95 national demonstration project involving about 6,000 patients in 24 geriatric hospitals, ten health facilities for the elderly, and nine nursing homes. This project was undertaken largely for publicity purposes, and the full report has never been disclosed, so the variance explanation is not known.

Although RUG-III attained the same high level of validation in these research projects it previously had in the United States, the Japanese government did not move forward with introducing RUG-III into LTC facilities because officials did not have enough confidence that they could overcome providers' opposition to a case-mix payment system. It had been hard enough to introduce flat-rate payments, and making this further step seemed premature, at the least. Moreover, the RUG-III validation projects had revealed how little experience LTC facility staff had in undertaking comprehensive assessments. Any case-mix grouping based on such assessment data would not be reliable, so focusing on quality rather than costs appeared to be the more appropriate goal.

The government's interest therefore shifted toward care planning, and in 1993 it decided to expand the assessment form used in the above-mentioned RUG-III projects to include the full Minimum Data Set (MDS). (Before this, the form had included only the items needed to group patients into RUG-III categories. One geriatrician remarked that the full MDS form filled in the gaps that had been missing.) The Resident Assessment Protocols (RAPs) were translated into Japanese, and the triggering mechanism explained to the users. Thus the RAI entered through the back door, so to speak, of the RUG-III case-mix project. In 1994, the RAI (1.0) manual was published and presented to providers as the care planning instrument recommended by the government. This marked the first time that the term *care plans* came into everyday use in LTC in Japan. Provider organizations using the RAI sponsored seminars throughout the country. Some nurses grew enthusiastic about the RAI because the assessment instrument gave them a new professional role and purpose. (Formerly, nurses had drawn blood and given injections, but these activities had come to be discouraged under the new, inclusive flat-payment system.)

#### **A DIVERSITY OF ASSESSMENT INSTRUMENTS**

At about the time that the care-planning phase was getting started, legislators began seriously discussing the need for a new public LTCI. As its design took shape, it became clear that two instruments would be required: one for determining eligibility and another for drawing up care plans. The former instrument would require both an assessment form and an eligibility algorithm, but RUG-III appeared to be too complicated and too medically oriented for this purpose, especially as the design of the LTCI shifted toward covering a greater range of social services. That the MDS items could have been utilized for developing an algorithm for deciding eligibility levels was not given serious consideration despite the fact that such an instrument, using 34 MDS items, had been developed and validated (Yamauchi et al. 1998). The government had invested too much faith in its own instrument, and its only concession was to incorporate 12 items on medical procedures into the assessment. The fact that the MDS items were protected by copyright presented another hurdle to the adoption of an MDS-based instrument. The government would have had to negotiate with interRAI if any changes had been necessary, which the government was unwilling to do.

Care managers needed an instrument for care planning that would enable them to assess need, set care goals, and arrange for services to be delivered within the amount set by the LTCI and the out-

of-pocket expenses that their clients were willing to pay. This was particularly important for the services provided in community settings. What the government needed was a home care version of the RAI. Thus, when *interRAI* started developing the RAI-HC, the government provided large grants for testing the reliability and validity of the pilot RAI-HC. The RAI-HC manual was first published in Japan in April 1996.

Even before the introduction of the home care version, however, a backlash had arisen against the original RAI for institutional care. Critics accused it of being too lengthy, too complicated, “over-medicalized,” and poorly suited to Japan. These detractors ignored the fact that the time needed to make an assessment does not necessarily depend on the number of items the form contains, but rather on the ease with which it can be filled out. They likewise ignored the need for detailed instructions in order to obtain reliable results, as well as the necessity that assessments be comprehensive. The providers’ low level of sophistication is indicated by their most frequent complaint against the RAI: that filling in the assessment form did not by itself enable them to draw care plans.

The opposition to the RAI became more focused as details about how the care-planning instruments would be used became clearer. Under the LTCI legislation, those eligible would be able to access any provider directly, but should the agency be not able to deliver the service needed, it would have to contract that service out to another agency. (This sort of situation is not an unlikely one in Japan, where most such agencies provide only a single line of services, such as visiting nurses or home help.) Providers would therefore stand to gain by using care-planning instruments designed to elicit precisely the “needs” met by their agencies,<sup>5</sup> and suited to their own care managers’ professional backgrounds. From 1995 on, provider organizations started developing their own care-planning instruments. The associations of LTC facilities, of visiting nurses, of social workers, and of care workers all proclaimed that their instruments were better and easier to use than the RAI or the RAI-HC, and they adamantly refused to give them up. As a result, when the LTCI was implemented, the government was forced to allow providers to choose any among five different instruments (the RAI-HC plus the four designed by provider groups). This means, in effect, that the government faces an insurmountable barrier to constructing a unified database for evaluating quality.

Despite these setbacks, a revised version of RAI 1.0, MDS 2.1, was published in May 1999. MDS 2.1 included revised items that were to have been incorporated into RAI 3.0 and that were also compatible with the second version of the RAI-HC (RAI-HC 2.0). RAI-HC 2.0 was also published in 1999, in September. The Japan *interRAI* Committee, which had been formed within a nonprofit research organization, HIT (Hokkaido Intellectual Think Tank for Regional Development),<sup>6</sup> was responsible for both MDS 2.1 and RAI-HC 2.0.

Because providers can freely choose among care-planning instruments, the Japan *interRAI* Committee has put its emphasis on improving the quality of care and on addressing the pressing needs of the care managers. The committee pursues the following strategies in promoting the appropriate use of the RAI:



1. Annually publishing a book of case studies that takes the reader through the process of assessment, triggering, and relating RAP and CAP categories to each case, and that shows how the information derived from the assessment should be used in drawing up the actual care plan.
2. Conducting “train the trainers” seminars in three locations for the purpose of training those who conduct workshops for prospective care managers that choose the RAI-HC.<sup>7</sup>
3. Conducting open seminars for care managers.
4. Encouraging the establishment of local study groups by sending committee members as lecturers, providing seed money, and so on.
5. Establishing a forum for the more than 20 RAI software vendors that the committee has approved.

#### **THE RAI'S LIMITED SUCCESS**

RUG-III introduced the case-mix concept and methodology to Japanese LTC. Indeed, since it predated the testing of the Disease-Related Group in the late 1990s, the RUG-III research studies discussed above could be said to have been the first time that a case-mix grouping system had been validated in Japan. The methodology for obtaining clinical and statistical cost data was also unique at that time. Prior to the RUG-III research, cost studies had been restricted to measuring the time spent at the patient's bedside; all activities not related to patient care (e.g., conferences, breaks) were appropriated equally. By expanding patient-specific time to include indirect care time, RUG-III made possible more accurate measurements, and this improved accuracy was reflected in cost savings.

The RUG-III validation studies showed that there was considerable overlap in case mix among the three types of LTC facilities in Japan. Although the average case-mix index (CMI) was higher for geriatric hospitals, nursing homes under the social services system had quite similar case mixes, and they also had a fair number of residents who placed in the higher RUG-III groups. The health facilities for the elderly had the lightest case mixes. At that time, the per diem payment to geriatric hospitals was about 50 percent more than that to nursing homes; per diems for nursing homes and health facilities for the elderly were at about the same level. These findings did not attract much attention when the report was first published in 1992. Since funding of LTC facilities has been unified under the LTCL, however, the public has become more aware of differences in payment according to facility type. The most recent study of the three types of LTC facilities, completed in 2001, showed results similar to the RUG-III validation studies (Kenporen 2002). Nevertheless, the application of RUG-III is limited to individual research projects, and RAI items are not used for determining eligibility.

The RAI's greatest success has been in introducing the concept of care planning based on comprehensive assessments to Japan. For the first time, clinicians have become aware of its necessity and value, and this awareness lays the basis for care teams' use of one uniform assessment tool. Despite provider organizations' efforts to promote their own care-planning instruments, RAI-HC

continues to be the most popular of the five instruments in the seminars conducted in each prefecture for prospective care managers.

The RAI and RAI-HC have been able to maintain their position because of the grassroots support by care managers and because of the government's funding of research studies, which have conferred a quasi-official status on the instruments. Care managers say that the RAI's advantage lies in the "triggers," which act as links between the assessment and care guidelines in specific domains. These links facilitate the setting of care goals and the monitoring of care. In contrast, when any of the other instruments is used, care managers must intuitively derive these key aspects from the assessment itself.<sup>8</sup> Some care managers with a non-health care background prefer the RAI because it provides them with basic knowledge about the medical aspects of care. These factors have contributed to the continuing popularity of the RAI, which is shown by the impressive sales of the RAI manuals.<sup>9</sup>

Despite this impressive record, however, it remains unclear whether the RAIs are actually being used appropriately. Most care managers are generally inexperienced, and their time is filled with billing and other administrative responsibilities. Even those using the RAI or the RAI-HC are not all assessing on a regular basis, as prescribed, or exploiting the protocols' full potential by integrating the results into their care plans. The vast majority of local governments lack the infrastructure that would enable them to audit the assessment forms and care plans. Moreover, even the few municipalities that have started monitoring have found their task complicated by the different care-planning instruments used by different providers.

#### LESSONS FOR THE FUTURE

Will this "bottom-up" approach—of waiting for providers to recognize the advantages of the RAIs—eventually succeed? Since a "top-down" approach, in which the government would have mandated RAI use, failed in Japan, this is the only option. On the positive side, no provider can complain that the RAI has been imposed by fiat: those who use the RAI are true believers in its merits and have adopted the RAI despite pressure from professional organizations to use their instruments instead. The RAI advocates' efforts to develop user-friendly manuals and software and to organize seminars to promote its use at the grassroots level have focused on enhancing the instrument's clinical utility rather than emphasizing its research and policy potential.

On the negative side, because RAI use is not mandated, data generated tend to be hard to collect, incomplete, and difficult to analyze. At present, there is very little awareness of the need to evaluate the quality of care based on individual data. The development of the database that does exist has largely been financed by royalties from the sales of RAI manuals. Whether the Japan interRAI Committee can continue to support such activities is uncertain, as the sales of the manuals are reaching the saturation point.

Reflecting on what might have been done better, we now wonder whether it would have been possible to cooperate with the government in developing the assessment form and algorithm for

determining eligibility levels. If MDS items had been used in the assessment form, they would have been embedded in the LTCI and integrated with care planning. This might have been possible if *interRAI* had adopted a more flexible attitude toward the copyright issue, because the government's concern lay in maintaining a free hand in negotiation rather than actually making substantive revisions. Cooperating with the government would have been difficult, however, because power in Japan is concentrated in the hands of bureaucrats who not only have the administrative responsibility of implementing policy, including contracting out policy-related research, but who also play a key political role in drafting new legislation, lobbying for support among politicians and arbitrating among the various interest groups. In the case of the LTCI, the major party that had to be placated was the social welfare lobby, so that when it protested about the "over-medicalized" nature of the RAIs, the government agreed to contract out the design of the assessment form and eligibility-grouping algorithm to the social welfare lobby's own research group. Adherence to scientific standards was a lesser concern.

This issue will be revisited in the near future because there is renewed interest in RUG-III. Once again, this interest arises from the need to reform hospital payment mechanisms. The new LTCI program's goal of containing health care costs through rationalizing LTC has not been fully realized because most hospitals have opted to remain under the old health insurance system and have not switched to LTCI. Thus, pressure is mounting to introduce case mix-based payment to hospitals providing LTC and subacute care. In fiscal year 2001, a government grant, under the auspices of the Health Insurance Federation, has been given to undertake a RUG-III validation study in eight hospitals, including a rehabilitation unit (Kenporen 2002). The fact that payment can be linked to quality audit is attractive to policymakers. *interRAI* will now have to make a strategic decision about whether to allow the use of its items for the proposed case-mix classification in subacute and long-term care financed by health insurance.

## NOTES

- 1 This trend started in 1973, when the decision was made to waive copayments for elderly citizens.
- 2 This includes 12 items on medical procedures such as stoma care, catheters, and so on, which were added under pressure from the Japan Medical Association.
- 3 Individuals can purchase services directly from providers without delegating the task to a care manager, but should they opt to do so, they must pay the full cost first and get reimbursed later for the 90 percent covered by the LTCI, besides having to deal with the complicated process. Consequently, virtually all choose to obtain their services through a care manager.
- 4 A comparative international study showed that Japanese LTC facilities had among the highest ratios of low-care cases, regardless of the criteria used to define "low-care" (Ikegami, Morris, and Fries 1997).
- 5 One aspect of the LTCI not given sufficient consideration at that time, however, is now acting as a check on such behavior: clients are able to choose or change their care manager whenever they

- wish. Thus, for example, a client wishing visiting nurse service would choose a care manager based in a visiting nurse agency.
- 6 HIT had been the contractor for government-funded RAI research and seminars since 1993. On April 1, 2002, it changed its name to the Hokkaido Intellectual Tank.
  - 7 All of those who pass the examination for care managers must participate in a 32-hour seminar that is held in each prefecture. This includes a workshop about the care-planning instrument of their choice.
  - 8 The only other instrument that has a similar triggering mechanism is that of the Visiting Nurse Association, which borrows many elements from the RAI-HC.
  - 9 As of July 2002, the MDS 2.1 manual had sold 32,058 copies; the MDS-HC 2.0 had sold 61,515; the Case Studies I (published February 2000) 11,320; and the Case Studies II (published November 2000) 5,020.

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## **EXECUTIVE SUMMARY**

In Spain, the growth of the elderly population and the resultant increase in the number of dependent persons has attracted much political attention, but, to date, policymakers have focused mainly on the pressing issue of pensions. Until recently, the tradition of families caring for their own elderly members meant that facilities for dependent persons were neither widely desired nor widely available but the social changes that create demand for such services (such as larger numbers of women joining the workforce) have unfortunately coincided in Spain with the current demographic shift, leaving the country extremely unprepared.

The sudden need to plan, set up, and monitor these new formal services in a sector with a paucity of information on needs, costs, and quality led to several experiments with the use of the Resident Assessment Instrument for nursing homes (RAI-NH) and the Resource Utilization Groups (RUGs) in the early 1990s, but because Spain is divided into 17 politically autonomous regions these early experiments were uncoordinated local efforts. In addition, the urgent need for information led to the RAI's being sold in some regions as an information system rather than as a combined clinical, management, and research tool, a move that proved to be a tactical error, as the RAI failed to gain the support of key clinical staff. RAI advocates also learned that mandating the use of the instrument as a quick-fix solution is a mistake, in that grudging cooperation does not generate the sort of consistent, quality information and care planning the RAI is intended to promote.

Nevertheless, the modest results of these early experiences have served to demonstrate the potential of the RAI methodology. Moreover, the fact that some regions now have RAI data highlights the lack of comparable information in others, creating a dynamic in which the need for and benefits of a more informed approach are increasingly obvious to all concerned.

Since 1998, representatives of all regions and of the national government have participated in discussions about implementing RAI instruments nationwide; such plans have been more warmly received by health-sector representatives than by those from the social care sector, for whom the use of standardized assessment instruments and comprehensive information systems is a less-familiar concept. In addition, the pressure on personnel and resources in this traditionally underfunded area has led to caution regarding the implementation of a complex and possibly burdensome new system.

Because of these concerns, the national project is not yet under way, but several regional governments have moved ahead, investing in training and software and joining forces with other regions more experienced in the use of the RAI in a coordinated effort involving the RAI-NH, as well as the RAI instruments for home care (RAI-HC) and mental health (RAI-MH). Experience to date suggests that the keys to successful implementation are (1) gaining grassroots support by promoting the use of RAI as a clinical tool and (2) using an incremental approach when introducing RAI evaluations and care planning into facilities so that staff do not find themselves overwhelmed.

On the policy front, proposals for a new law on dependency were due to be formulated by mid-2002, but have not yet been circulated; RAI instruments may have an important role to play in

defining degrees of dependency for eligibility and co-financing purposes, as well as in controlling quality in the long-term care sector.

## INTRODUCTION

In 2000 Spain had a population of 40.5 million distributed throughout 17 regions, called Autonomous Communities. Six and a half million citizens were aged over 65; 775,000 lived alone, and, of these, 170,000 suffered from some degree of dependency (SEGG 2000). The growth of the elderly population has been rapid: between 1960 and 1998 the percentage of the population aged over 65 rose from 8.7 percent to 16.3 percent, generating a considerable deficit in resources.

In Spain, health care is free for all at the point of use and funded from the General Budget. Total health resources amount to 7.1 percent of gross domestic product, and public-sector health resources represent 5.4 percent of GDP (as compared to the European Union mean of 8 percent and 6.1 percent, respectively, in 1998). This public health care budget has been entirely decentralized as of 2002.

Responsibility for personal social services is completely decentralized. Regional governments manage and fund these services on a means-tested basis. Public financing is scarce, however: only 30 percent of the total expenditure on personal social services is publicly funded.

As might be expected, the current situation in Spain in the area of health and social care for dependent persons is intimately bound up with the rapid growth of the elderly population (Morán 1999). Although until recently attention has mostly focused on the impact of these changes on pensions, the mounting costs generated in other areas of this sector are now becoming a cause for concern. There is much debate about increasing health care expenditures and, to a lesser extent, about the costs of long-term care. It has been estimated that annual health care costs for those 35 to 44 years old average 120,000 pesetas (about US\$630), whereas those for people aged 65–74 average four times as much. True, the health expenditure generated by a sick elderly person is not necessarily greater than that generated by a sick younger person, but as the burden of ill health is skewed heavily toward the elderly population, the elderly as a group incur very high health care costs, which must be taken into account and planned for in an aging society.

Of the 7.1 percent of Spain's GDP that is spent on health care, 40 percent is spent on the elderly. In this respect, the situation is positive for the elderly, given that they receive a higher proportion of a comparable total (adjusting for income) than in other developed nations. In addition, older people are exempt from existing copayment arrangements, principally with regard to the cost of prescription drugs.

For the 170,000 dependent persons currently living alone, formal long-term care—whether public or private—is very scarce. Public-sector long-term care is especially limited, accounting for only 4 percent of all home care and 40 percent of nursing home beds.

Social care and health care services are closely linked, but placements are not always appropriate. Where health resources are scarce, elderly persons may not always gain access to optimum care, even if their medical conditions might benefit from active management in a specialist unit. Others who

might be more appropriately cared for in a community setting may find themselves marooned in hospital beds, awaiting the availability of suitable accommodation. Obviously neither of these scenarios represents an adequate use of health and social care resources, nor is the system beneficial to elderly people; both under- and overtreatment in the acute hospital sector need to be addressed if provision of care for elderly persons is to be adapted to their needs and equitably distributed.

### **Aging and the Need for Social Care**

In Spain's Social Care System, there is an important information gap that relates to, and is to some extent the cause of, the absence of debate on these issues and the ongoing, excessive faith in the ready availability of informal care. As has been said, the debate on pensions has obscured the whole area of care provision and other costs related to aging. The usefulness of the information that does exist is further compromised by the lack of comparability between the studies that have been done, which have used different methodologies.

Most of the work in this field in Spain classifies individuals according to functional capacity, either by the number and nature of the activities they cannot carry out or by different scales, such as those developed by Katz or Lawton. Such information is insufficient for service-planning purposes because it does not take into account current support systems (formal or informal), economic need, or many other factors. To date, only one study, based on multivariate analysis, has permitted a more rigorous, "ad hoc" classification of elderly individuals.

Almost no information exists at national level; what there is derives from National Health Surveys (MSC 1995, 1999) which have not been systematically analyzed. Further information on disabilities is also available from the National Survey on Impairment, Disability and Handicap (INE 1999) and from another survey, Informal Support for Older People, conducted in 1994 (CIS 1996), which classifies dependent persons according to those activities for which they require help. Of greater interest is the Survey on Loneliness in Older People (CIS 1999), which collected data from 2,500 individuals regarding the degree of help they required for twelve different activities.

Some interesting information emerges from all these data. In Spain, 65.9 percent of those aged over 65 are independent; 20.8 percent are dependent only for instrumental activities of daily living (IADLs), and 13.4 percent are dependent for both IADLs and basic activities of daily living (ADLs). This tells us nothing, however, about the different types of help required by people within the same level of dependency. Nevertheless, it is known that age, poor health status, and a low educational level are all positively associated with dependency.

### **Social Care and Nursing Homes**

In Spain, the three institutions associated with social care are (in order of importance) the family, the private sector, and the state. The bulk of long-term care provided in the home setting is delivered by



family members, usually by offspring and especially by women. Eighty percent of dependent persons receive only this type of informal care. Formal care in institutions, including both public and private day care and residential care, and without any type of informal support, is only available for about 6 percent of dependent persons. Publicly funded home care, with or without additional informal support, reaches only 100,000 persons out of a total of 2.15 million disabled persons. Finally, about 260,000 people rely on private home care.

Interestingly, dependent persons living in their own homes occasionally use daycare centers, which provide some respite for stretched family caregivers. It is not possible to identify precisely how many of the scant 7,103 existing spaces are public and how many are private, but in any event it is clear that provision is minimal.

Overall, there is no countrywide information on the proportion of nursing home residents who are dependent in ADLs, although extrapolation from small, local studies suggests a figure of about 75 percent.

Two types of nursing home placements are available in Spain: private placements, whose cost is borne entirely by the user, and publicly funded placements, for which central state funding or financing from regional or local authorities covers part of the cost. All elderly persons in Spain receive a pension (the minimum pension is 42,000 pesetas [US\$224] per month; the average is 82,000 pesetas [US\$436] per month), and all nursing home residents are required to contribute about 70 percent of their pension to the cost of their care. Publicly co-financed beds may be in state-run facilities or in privately run facilities with beds contracted by the state. From the point of view of the user, funding and services are the same in either case. The state determines who has priority for access, which is mostly based on the economic and family circumstances of the applicant. Whether or not they have children, persons who live alone receive top priority, with the degree of severity of their physical and mental problems also receiving due weight. Entrance criteria, however, vary by region: in some areas poor economic circumstances carry a lot of weight, so that persons who are less dependent but very poor receive higher priority for publicly funded nursing home beds than do more dependent persons who are slightly better off economically. It might be thought that this would cause strange anomalies, but in practice these rarely happen: public provision is so scarce that virtually all persons who finally make it to the top of the waiting list for a publicly funded bed are not only poor but also very dependent.

Beyond the elderly and the physically dependent, persons with mental health problems are another key group presenting a complex mix of health and social care needs. Again, quality information at a national level is lacking, and in the current climate of closure of long-term care institutions and the corresponding shift toward a range of community-based services, there is an urgent need for such information if these services are to address the key needs of this vulnerable group.

The current paucity of relevant information not only affects the ability to plan and predict demand but also has implications for the running of residential and community-based facilities for quality management. Consumers (potential users and their families) also lack adequate information on the current availability and quality of resources—or even knowledge of their existence. Media

scares and scandals arise with a certain regularity, focusing on horror stories occurring within a sector that is characterized by lack of transparency.

Finally, available data allow us to affirm that the free market—that is, private provision with no state financing or state-determined access criteria—accounts for 61 percent of total current nursing home beds, with the remaining 39 percent publicly co-financed either in state-run facilities or facilities with state contracts.

In summary, the current situation is characterized by a severe deficit in resources and an excessive reliance on informal care, particularly with respect to care of the elderly. This reliance will prove less and less workable over the next few years, as social changes—smaller families, increased family dispersion, ever smaller flats and houses, greater participation in the workforce by women—create an increasingly difficult situation for the 78 percent of disabled people who until now have relied exclusively on informal care. A situation in which only 6 percent of dependent persons live in nursing homes, public or private, and only 7 percent receive any sort of help from public services is unsustainable, and central and regional governments must undertake a considerable increase in the provision of formal home and residential care, as well as develop incentives to ensure such care is properly regulated. At present, there is no national strategy that adequately addresses all the dimensions of the current crisis in care for elderly and dependent persons. To date, efforts at improvement in services for the elderly have tended to be incremental, avoiding breaks with tradition, and although the need to tackle the situation afresh is clear to many, the process of change is only just beginning.

#### **FIRST STEPS TOWARD RAI IMPLEMENTATION**

Interest in the use of the Resident Assessment Instrument (RAI) family of assessment instruments has arisen in Spain within this context. The changes and difficulties that have sparked this interest have occurred throughout the country, but because Spain is divided into 17 Autonomous Communities, each with its own regional government, different regions originally began trying out the RAI in different ways. Different Autonomous Communities have until recently had differing degrees of responsibility devolved from the central government: some were entirely responsible for running their own health services and thus had a great deal of freedom in setting priorities and investing in new technologies or programs, whereas others remained tied to the older, centralized health service structure, the INSALUD. These differences, as well as historic differences in wealth, levels of service provision, and budget share, have led different regions to begin tackling their sociodemographic problems from different starting points.

During the early 1990s, three regions tried out instruments based on the Minimum Data Set (MDS) at the service level, and a few research studies were carried out elsewhere. These early experiments occurred independently, in parallel rather than as part of a coordinated effort. The next sections describe the three main initiatives; these case studies are then followed by a discussion of how these separate activities are now beginning to act synergistically to influence policy at the national level.

## Galicia

Galicia is a geographically isolated region in northwestern Spain with a population of approximately 2.7 million. Although not the poorest region in the country, it is an underdeveloped area with little industry; many Galicians earn their living through fishing and small-scale agriculture. For a long time, many young people have left Galicia in search of employment elsewhere, leaving families depleted of their younger members. Many of those who leave, however, return to Galicia on retirement to spend their last years in their native land, further increasing the proportion of elderly people in Galician society. In 1996 the proportion of those over age 65 had reached 18.3 percent in Galicia, compared to a national average of 15.6 percent.

The central government transferred full responsibility for the running of the health service to Galicia in 1992. A structural reorganization following the reelection of the Partido Popular in the regional government elections in late 1993 resulted in the merging of the regional Ministry of Health with the Ministry of Social Services—potentially a landmark event. Historically, professionals and policymakers in both sectors had struggled to provide seamless, coordinated care in a situation with two separate organizational and financial structures, but the merging of budgets and responsibilities under one regional government minister had the potential to greatly facilitate the coordination of activities and financing and to streamline the transfer of personnel or funds across the health care–social services divide. Although the Galician health service (SERGAS) and the General Directorate of Social Services continued to exist as separate entities, proposals to create a new coordinating unit, the Programa de Atención Sociosanitaria (PASOS) underlined the political intent to create better-integrated services. After prolonged discussion and preparation, the new unit finally came into being in February 1996. Its mission was to design, develop, and manage

a model of coordination of social/health care in Galicia and its practical application. In addition, the department will function as a coordination unit . . . with regard to the elderly, palliative care, mental health, and handicapped persons. PASOS will also be responsible for the definition and overseeing of specific social/health care programs leading to a more integrated service with continuity of care between social services and health services. (Diario Oficial de Galicia 1996, 1998; Plan Estratégico 1999)

Some in Spain disagree with the merging of health and social services in this way. Critics express concern that the creation of the *espacio sociosanitario* (“sociohealth space”) underplays the health needs of dependent persons, shifting the focus from health care (expensive) to social care (less expensive) and that such mergers shunt dependent persons, in particular the elderly, into a second-class care network, denying them access to the more medicalized care their conditions might warrant. Debate continues as to whether the *espacio sociosanitario* really exists or whether health and social needs can be met perfectly well without the need for additional client categories, with the dangers such classification might bring.

These considerations notwithstanding, the new PASOS team in Galicia believed that the potential benefits of such a merger were clear. Keen to get going, the team asked itself key questions, such as, “Who are our clients?” “Where are we at?” “What are the strengths and weaknesses in the current system?” Immediately, the team encountered its first obstacle: nobody knew the answers.

As all the contributors to this Milbank Memorial Fund study of RAI implementation internationally point out, information systems are a key area to be addressed in the complex arena of long-term care delivery. As in the acute care arena, LTC providers and policymakers need basic data on the number, distribution, and turnover of clients as well as information on their diagnoses or problems in order to plan and distribute current services, observe trends, and project future needs and costs. Unlike acute care, however, LTC has not traditionally pursued this kind of strategic approach, because LTC has grown from a multiplicity of charitable roots rather than a system of state-funded entitlements.

The fact that care has been given by such a wide range of independent providers—beginning with the huge amount of care provided by families, moving through the considerable provision offered by religious and charitable organizations and on to means-tested social service provision for the needy and private provision for the better-off—has meant that, historically, LTC delivery has not taken place within any sort of overall framework but has instead occurred on an ad hoc basis according to the criteria of the provider(s) in question. In Spain, specific facilities or organizations might have their own systems for prioritizing or delivering care, but at a national or regional level no overall strategy or unified criteria were in place. Even state-run nursing homes, despite the huge amount of health care they provide, remain within the realm of social services and so have missed out on health service strategic planning initiatives and information technology (IT) development. Mental health services have similarly missed out, because for a long time they did not form part of mainstream health service provision in Spain but were governed under separate arrangements. Thus, at the time PASOS came into existence, the ever-underfunded Directorate of Social Services in Galicia, whose ethos had traditionally centered on simply providing what help it could to the most needy, had not evolved to a point where the need for a more strategic approach was generally accepted, and no overall clinical information system was in place. The culture change needed to develop such a system was to prove a great challenge, and the lessons learned in this transformation are highly illuminating.

Faced with this situation, policymakers in PASOS and the new, joint regional ministry decided that setting up an information system for LTC facilities was a priority; of the various systems available, they chose to adopt the RAI for nursing homes (RAI-NH) (Calvo et al. 1999).

Thus, the launching of RAI instruments has come about using a different approach to that used elsewhere. In many countries, RAI instruments have first been adopted as research tools in a university department or through the initiative of clinicians, whereas in Galicia they were mandated by managers. Such an institutional approach has obvious dangers: although the needs and priorities of clients are the legitimate end of policy decisions, the link between client needs and policy decisions can easily get lost as management priorities take over and client needs are pushed into the

background. In the case of Galicia, the “top-down” approach to RAI implementation has had both positive and negative effects, as will be discussed later in this study.

The PASOS team brought in an outside consulting firm to provide “train the trainers” courses and materials; at the same time, there was a need to develop basic software to enable data to be keyed in at the facilities and stored in a central database. Two unfortunate things occurred at this point.

The first involved a misapprehension of the extent of the RAI-NH instrument. The consulting firm had provided a rather idiosyncratic version of the RAI-NH—a Spanish translation of the RAI-NH 1.0 quarterly form. All concerned apparently thought that the term “quarterly” meant that the 300 items on this form represented only one-quarter of the items included in the full version. This mistake (the quarterly form actually contains about 60 percent of the items in the full version) led the team to reject the idea of introducing the full RAI-NH, which in their minds contained upward of 1,200 items, as too Herculean a task, and it opted instead to introduce only the quarterly form, with corresponding software based only on these items.

The second decision—one that, in retrospect, proved prejudicial—involved the way in which the RAI was “sold” to LTC facilities. Although the perceived need for an information system was what had led policymakers to get behind the RAI, this kind of rationale is not nearly so important to those professionals—nurses and care assistants—who are closest to the residents and therefore most crucial to an MDS-based system’s successful implementation. The clinical applications of the RAI—its value as a multidimensional geriatric assessment tool and as an aid to care planning—make it highly marketable to these professionals, but Galician policymakers did not emphasize these aspects of the RAI when introducing it. As a result, nurses and other caregivers saw it as little more than a data-collection exercise, with all the negative connotations that this carries. Traditionally, clinical staff, who are trained to give priority to direct patient care, dislike the administrative parts of their jobs. Generally, they see paperwork of any sort as unimportant, time-consuming, “not my job,” and, in some cases, as an unwanted means of control by administrators.

Thus, although staff training in the use of the RAI included information about the instrument’s clinical, care-planning applications, no one provided either suitable software or even any sort of paper-based system for care plan development. This omission created the widespread notion that the RAI was essentially an information system for others’ use. Policymakers were not, at that time, interested in whether clinical staff used the data they collected in their daily work; what they wanted were the data, and they failed to appreciate the strategic need to achieve staff “buy-in” in order to obtain this result. The Galician government mandated use of the RAI by all private providers with nursing home beds contracted by the state and in 1998 made this a statutory obligation for publicly run facilities, as well (the RAI has initially been introduced to the latter facilities as a “recommendation”). The fact that the mandate would not, by itself, ensure timely, accurate data collection was not understood or was pushed aside. As frequently occurs in bureaucratic systems, the need to actively develop cooperation and shared goals with those further down the ladder was not taken into account, as this runs counter to the facile notion of a smooth “chain of command.”

In these early years RAI implementation was slow and difficult. Clinical staff's struggle to come to grips with the system via the intermediaries from the consulting firm, language difficulties associated with working with translated materials developed elsewhere, and insufficient information led to misunderstandings and hampered progress. Elections at the national level resulted in key people moving away to other posts; suddenly the PASOS program, initially set up on a modest scale but with high hopes and a view to expansion, found itself marooned in the no-man's-land between health and social services with an unclear role, few "teeth," a minimal budget, and a skeleton staff.

Nevertheless, the team persevered, organizing the training of facility staff and providing IT setup help. But this was not enough to overcome the huge barriers that existed to the use of assessment instruments and computers in nursing homes. The initial error regarding the meaning of "quarterly" went unchallenged for years (with facility staff holding the mythic "full version" of the RAI in horrified awe as an instrument of the devil whose implementation must be resisted at all costs); inputting data using the uninspiring, homespun software was a chore; and the erratic and reluctant manner in which facilities collected and transmitted data meant that the potential of the system was in no way being exploited. Added to this, any strategies to improve the acceptance of the RAI and, in turn, the regularity and quality of data collection were difficult to implement, because nursing homes continued to be the exclusive responsibility of the General Directorate of Social Services; without its key support, little could be achieved. Unfortunately, continued ambivalence within the historically independent realm of social services regarding the purpose of and need for the newfangled information system (and, indeed, the newfangled PASOS program) meant that unequivocal support was not forthcoming; facilities thus received a mixed message, and little progress was made.

Faced with something of a stalemate, the PASOS group decided to turn its attention to the area of home care, hopeful that collaboration with health services via the more forward-thinking Directorate of Primary Care would be more fruitful. Because nursing homes in Spain represent only a very small part of overall care provision for dependent persons, the need to provide a more formal assessment, care planning, and information gathering system for the home care setting is ever more urgent. In 1998, work along these lines began with the translation of the RAI for home care (RAI-HC) into Spanish and a spate of training courses for community-based nurses. Again, however, the limited authority of PASOS meant that implementation required the collaboration of the Subdirectorate of Primary Care. Although initially there had been interest, as time went on enthusiasm for the project waned, personnel and priorities changed, and the initiative floundered. Political rhetoric about the desirability of home care was not matched by a corresponding level of investment and political commitment; the construction of nursing homes has continued apace and the structural and attitudinal changes necessary for developing home care as a viable alternative have not yet been seriously tackled.

Nevertheless, new developments at the national level were just around the corner, and the groundwork that had been done on the RAI-NH and RAI-HC in Galicia was to be put to good use.

## Cataluña

Cataluña (also spelled Catalonia) is a modern, industrialized region in northeastern Spain with a population of about 6 million; 16 percent of Cataluña's people are over the age of 65. Situated on the French border, it is perhaps the most "European" of Spanish regions and one of the richest parts of Spain. Like Galicia, Cataluña is one of the historically independent Autonomous Communities, and the region has full responsibility for running its own health service.

Because of the different historical financing structure of the Cataluña health service, interest in the RAI on the part of the Administration focused mainly on the Resource Utilization Groups (RUGs). A strong infrastructure composed of multiple insurance-based health service providers meant that when universal health care provision became the norm throughout Spain, the model adopted in Cataluña was essentially one in which the state contracted out services to multiple providers. In such a situation, the need to organize appropriate reimbursement systems is a key issue, and one of considerable complexity. Although providers are interested in the care planning and quality control aspects of the RAI instruments, these applications have not so far been a priority area for the Cataluña health services.

The creation in 1986 of the *Vida als Anys* ([Adding] Life to Years) program was a key move in the transformation of long-term care, integrating health and social services for the sick elderly, the chronically sick, and those in need of terminal care (Programa *Vida als Anys* 1998; Salvá et al. 2000). The program was co-financed by the General Directorate of Health Service Economic Resources (DGRESS) and the Catalan Institute of Social Services and Assistance (ICASS), with both entities under the jurisdiction of the Department of Health. This *modelo sociosanitario*, nevertheless, was still distracted by the need to differentiate between the "health" component (since Spanish citizens have the universal right to free health care, at the point of access) and the "social" component (since those who receive social services can be charged according to their means). Given this complex situation, providers indulged in various forms of gaming (e.g., admitting a disproportion of light-care cases). In an attempt to redress this imbalance, rationalize admission criteria, and restore equity, policymakers made the decision in the early 1990s to adopt a case mix-based payment system. Policymakers looked to the United States for inspiration and, given the limited applicability of Diagnosis Related Groups (DRGs) outside the acute sector, chose to follow the lead of the U.S. Health Care Financing Administration (HCFA) and considered using the RUGs for medium- and long-stay patients.

By 1995, initial trials with early versions of the RUGs were being abandoned in favor of the more detailed RUG-III classification, but despite progress in the collection and analysis of RUG-III data, Cataluña has not yet implemented a case mix-based payment system. A RUG-III cost validation study, applying real Catalanian times and salary scales, is currently under way, but RUG-III is still regarded as a complementary tool (adjustment tool) for payment.

Since 1994, regular cross-sectional studies of the clinical and management applications of the RAI have been performed in both long- and medium-stay units, and detailed information on the

clinical characteristics of these populations (on the facility level and in the aggregate) has been fed back to providers (SCS 1996). In 1999, Cataluña mandated use of the RAI-NH 1.0 (in an early Spanish translation), and providers have access to annual reports containing epidemiological data on clinical characteristics, outcomes, and comparisons between health care areas.

Despite these efforts, the strong tradition of contracting out services to private providers, which so characterizes health services in Cataluña, has impeded progress toward universal implementation of the RAI. For example, whereas policymakers elsewhere have earmarked public funding to facilitate training, assist in software development, and so on, this approach has won few followers in Cataluña, where care providers have largely been left to fend for themselves when setting up assessment instrument-based initiatives. Because of this, policymakers are not in a position to insist on the use of any one particular instrument or information system in a sector characterized by economic fragility, and although it is accepted that the RAI is the most developed technology in this area, adoption of the full MDS with all its components (RAPs, care planning, quality indicators [QIs], etc.) is seen as a gradual process. Individual providers continue to decide for themselves if and when to expand beyond the minimum requisite MDS 1.0 data.

Around 1997, the RAI-CAT (RAI Cataluña) group formed, in response to providers' interest, as a means of promoting the wider application of RAI methodology. Even so, the RUG system's potential to function as a stepping stone to the wider application of the RAI in care planning and quality control has not been fully exploited. To date, progress has been modest, and it will remain so until policymakers make a firmer investment in "marketing" the RAI effectively.

## **Madrid**

Madrid, Spain's capital, is a densely populated city with about 3 million inhabitants in the city proper and a total of 5 million in the Autonomous Community of greater Madrid. Persons over the age of 65 make up 13.5 percent of the population. Until 2002, health services for the Madrid area were not devolved but were still run by INSALUD, while personal social services, as in the rest of Spain, are funded and organized by the regional government of greater Madrid.

In the Madrid area, the use of the RAI system initially arose as part of a quality initiative on the part of the Regional Social Welfare Service (Servicio Regional de Bienestar Social, or SRBS). SRBS officials, conscious of how far services were being stretched as demographic changes kicked in and also aware of the increasing demand by consumers and their families for quality care, began to develop a plan to address quality issues in facilities for the elderly (SRBS, no date). Part of this initiative centered on identifying appropriate staffing levels and, therefore, on the need to classify residents according to functional levels and associated workloads. To aid in this, the SRBS introduced the RUG-I system (based on the MDS) in 1996, and developed supporting software. Researchers classified residents in 19 of 25 facilities run by the SRBS according to the RUG-I case mix system and observed some interesting things, in particular, that the case mix of a facility bore no relation to the



type of facility it supposedly was. Facilities designated “nursing homes” had the same proportion of light cases as those designated “residential homes.” Unfortunately, this interesting initial effort using an MDS-based tool was put aside as leadership and priorities changed, and the IT network set up to transmit data around the system fell into disuse.

In 1998, a new initiative using the MDS began in Madrid, again via the SRBS, but this time with a highly clinical slant (Burgueño et al. 2001). The SRBS devised an ambitious project with a strong focus on the training of clinical staff, the development of suitable forms to be used by care assistants to record care processes, and “before” and “after” studies using the MDS quality indicators to assess the impact of the new, multidisciplinary way of working. Knowledge of the RAI methodology was to become a requirement for staff and incorporated into job descriptions; incentives were to be devised; and new care-assistant coordinators, who would be responsible for overseeing all the documentation and the application of the care plans, were to be designated. Ten facilities were selected to pilot the use of RAI, and one particular center was designated for full implementation of the new plan.

A year and a half into the new project, all concerned were reeling from the impact. Although staff in the principal pilot center perceived the RAI system as beneficial for residents in terms of the increase in multidisciplinary working and the systematic evaluation of residents’ needs and problems, it had proved impossible for staff to keep up with the new initiative in all its facets, and a sense of confusion and disarray prevailed. Record keeping was inadequate, and staff were unable to carry out evaluations at the required intervals. As a result, an “assess and file” approach to the MDS developed without the required follow-through to the use of the RAPs and the drawing up of care plans. Evaluations were carried out “in bulk” and in a rushed manner, and RAI-type integrated care planning did not mesh well with the facilities’ traditional, task-based approach. “Too much too soon” seemed to be the prevailing opinion. In response to this, the SRBS slowed down the initiative, but further managerial reshufflings meant that key people were no longer available to oversee the project, and so yet another RAI initiative was put aside.

### **Other Efforts**

Meanwhile, other projects in Spain were exploring various uses of MDS-based systems. For example, the Autonomous Communities of Valencia, Madrid, and Cataluña undertook a joint project to validate RUG-III against the PLAISIR system developed in France (Carrillo et al. 1996; Tilquin 1993). In Asturias, an RAI research group formed. And in the Canary Islands clinical geriatricians tried out RUG-III as a means of differentiating different levels of care (Alastuey et al. 2000).

### **NATIONAL DEVELOPMENTS**

The story so far has been a tale of disconnected, sporadic, and at times benighted projects in different parts of Spain, but these initial efforts did serve a purpose (Calvo et al. 1999): the seeds had been

sown. In 1998, as a result of a conference in Santiago on the RAI system, at which an Italian *interRAI* fellow, Roberto Bernabei, had spoken, a meeting took place between Bernabei and representatives from the Ministry of Health, the PASOS program, and those working with RAI in Cataluña (PVAA). Despite the setbacks, those with firsthand experience believed that the RAI system had potential in Spain as a means of unifying criteria, developing compatible information for use within the LTC sector, and, ultimately, improving quality of care. The meeting's participants therefore decided to join forces and try to create a national project with a licensing agreement to be signed on the use of RAI instruments covering the whole of Spain (rather than separate regional agreements). At that time the PASOS group was in the best position to produce a set of official translations of the RAI family of instruments, and it was agreed that PASOS should be the lead group in Spain for this purpose. The expectation, however, was that once this phase was completed, the central government would adopt the project and coordinate the distribution and implementation policy.

This was the beginning of a more fruitful phase. The direct connection that had been established with the *interRAI* group meant that the need to work through consulting-firm intermediaries was eliminated. Work began on the translation of the most recent versions of four *interRAI* instruments (NH, MH [mental health], PAC [post-acute care], and HC). Pieces of the puzzle began to fall into place as the full MDS 2.0 became available and the function of its different elements (RUG-III, QIs, RAPs) as well as the interrelationships between the various RAI instruments became clear.

The RAI-España project progressed as the idea was put forward in various official forums in which representatives of all regions, not just those currently working with RAI, participated. In a country just breaking free from a 40-year tradition of strong central government control, however, achieving a balance between national and regional decision making continues to be a challenge, and reaching agreements can be a lengthy process. Certain regions value their hard-won autonomy so very highly that any perceived imposition by the central government is not well received; on the other hand, the relative newness of the regional government setup means that those involved have had limited experience in how to successfully negotiate collaboration between regions.

In addition, the fact that the RAI instruments are designed for use with persons who have both health and social care needs means that it is important for professionals from both health and social care disciplines to be involved. So that both sectors would develop a sense of "ownership" of the RAI-España project, the Ministry of Health and the Ministry of Work and Social Affairs sought a joint agreement with *interRAI*. By late 2000, the agreement had not been signed, but some progress had been made: the Comisión de Aseguramiento y Planificación Sanitaria had put forward a proposal on the nationwide adoption of RAI methodology to regional representatives, and the plenary session of the Consejo Interterritorial had ratified the proposal on December 18, 2000. Discussions had also taken place regarding the use of the RAI/MDS as the basis for a national database analogous to the acute care sector's DRG database.

Since then, however, an important change has occurred. The old INSALUD (the centrally run national health service) was dissolved in January 2002, and all regions are now responsible for their

own health services. Because of this structural change there have been many changes of personnel in the Ministry of Health in Madrid, and the RAI-España project has suffered. The possibility of a national agreement coordinated by the central ministry has receded, and it now looks as though each region will have to sign up for the RAI project individually. In view of this, the Galician ministry has taken the lead by formalizing an agreement with *interRAI* for the Galician region. All this serves to highlight the difficulties of progressing with long-term projects such as RAI in a constantly changing political environment.

Meanwhile, on the grassroots level, clinicians, facility managers, and local management teams in many regions have demonstrated interest in the RAI. In Cantabria, a new combined Directorate of Health and Social Services for dependent persons has been set up and has organized staff training with a view to the implementation of the RAI-NH and RAI-MH in all relevant facilities. Plans to launch the RAI-NH are also under way in Aragon. In Madrid, the SRBS is studying the possibility of using RAI data to set up a single-point-of-entry system. Interest in the RAI-HC also increased, with Galicia undertaking a large-scale, population-based needs assessment that used this instrument to look at care needs and their distribution among the noninstitutionalized elderly. And Cataluña, Castilla Leon, and Galicia have joined forces to finance support software for the RAI-MH.

Pending the full-scale adoption of the RAI-España project at the central level, the PASOS program was acting as the main coordinating center for much of this activity. Training continued to be a priority, and, to meet the growing need throughout Spain, it developed and piloted a new distance-learning course in 2001. On the IT front, once the RAI translations were completed, attention turned to the need to incorporate the instruments into updated, user-friendly software—both to support the Galician initiative and to facilitate the rollout of MDS-based systems in other regions. This software was developed, and the software company formalized a contract with *interRAI* to produce and distribute RAI-NH software commercially. Data sets (dating back several years) for Galicia and Cataluña are now available, and, even allowing for the fact that neither is based on the full MDS, it is possible to observe certain trends.

Nevertheless, the challenge remained of introducing the full instrument so that all the investment in training and IT could be taken advantage of. And on this front, too, an important setback has occurred. Following regional elections in Galicia in September 2001, health and social services again separated into two ministries; the PASOS program and the RAI database came under the auspices of the health ministry, while residential facilities for the elderly were placed under the social service ministry. Coordination has been difficult, and work using the RAI-NH in residential facilities has stopped and started. It is possible, however, that this situation may undergo another reversal within the next few years.

Despite these recent setbacks, the RAI continues to make progress in Spain. Professionals and managers increasingly perceive the need for tools such as the RAI family of instruments at the health care–social care interface, and they appreciate the benefits of a common language to the complex and rapidly expanding area of LTC provision.

The early work with the RAI has undoubtedly had an impact on this progress. Though some projects have proceeded slowly, and some have been aborted, the experience gained has been valuable, and the pioneer groups have certainly raised awareness of the issue of multidimensional assessment and information systems at the health care–social care interface. As with other forms of cultural change, there was an initial phase of sporadic activity by “mad enthusiasts” whose work was initially dismissed but gradually gained ground and aroused interest. In 2002, the annual Health Care Management and Cost Evaluation Conference sponsored by Madrid’s SIGNO Foundation for the first time included a symposium devoted entirely to classification systems for the medium- and long-stay sector. A number of key people were invited and presented RAI-related projects. RAI technology now forms part of the National School of Health Studies’ management curriculum for the LTC sector. Several postgraduate nursing courses now include units on the RAI and multidimensional assessment. Without the experience and expertise gained in the early phase, none of this activity could take place.

At a management level, the fact that there are now people around who can say, “We’ve been using this, and what we’ve found is this” makes MDS-based assessment an attractive proposition for regions starting to set up information systems in the LTC sector—much more attractive, that is, than alternative systems with which no one has any experience. Understandably, managers can feel nervous when faced with the prospect of instigating major organizational change; they may perceive the need, but they worry about the unforeseen consequences of their actions. Where time spans are lengthy and budgets are large, these anxieties increase, so the experience of others “who’ve been there” is of paramount interest. That these experiences have not been entirely positive does not matter—managers know and accept that few projects are unqualified successes, but they do feel better when they have some idea of what to expect. Equally, the fact that the RAI is being introduced in many other European countries as well as being used in the United States increases its appeal, because policymakers familiar with acute-sector DRGs immediately grasp the advantages of using a data system that is internationally recognized and internationally compatible.

All the same, it can probably be said that, to date, the main impact of RAI data on policymaking and policymakers in Spain relates not to the content of the MDS data but to the simple fact that the data exist. So far, Spanish clinicians, managers, and researchers have made little use of any of the information, and if there has been any improvement at all in the lives of elderly persons attributable to the implementation of MDS-based assessment, that improvement remains to be defined and documented. What is undoubtedly true, however, is that the advent of the RAI has produced an irreversible shift in perspective among those responsible for service planning and provision. We now speak of a “before” and an “after” in long-term care, and before and after are defined in relation to the RAI. For the first time, the “content” of nursing homes can be described in a standardized format, with facts and figures; graphs can be drawn of RUG-III weightings, and quality indicators can be derived. This may only be true in a small number of facilities, the data may be out of date, and the coding may even be wrong, but in a certain sense this does not matter: the implications of the system are profound, and in many senses a point of no return has been crossed. Progress may be erratic and unnecessary duplication of work may continue to occur as new

regions pass through the initial phases of RAI roll-out, but although it is possible to procrastinate by “reinventing the wheel,” it is not possible to *uninvent* the wheel.

## **LESSONS LEARNED**

Experience and hindsight always reveal many things that could have been done differently, and the implementation of RAI in our setting is no exception. Among the many lessons that can be learned from the Spanish experience, three in particular can be highlighted:

1. The need to promote the RAI as a clinical system rather than an information system
2. The need to be clear about the nature of the task and the resources to see it through, and to be realistic about how much clinical staff can be expected to take on within a given period of time
3. The realization that an institutional mandate does not obviate the need to gain and maintain grassroots support

Each of these lessons is worthy of being discussed in detail.

### **The RAI as a Clinical System**

Much as it may frustrate those responsible for setting up and running information systems, clinical staff often fail to be enthused by them. This is true for several reasons, some “good” and some “bad” but all relevant. It is important to identify and address cultural obstacles, not just ignore them.

Even when explaining the system to managers and policymakers, who it might seem would focus especially on the information system, quality assurance, and financing applications of the RAI, it is important to get the “clinical relevance” point across very clearly. Otherwise this message will be lost when these people, in turn, set about implementing the system in their facilities. A single, unfortunately worded memo communicating the imminent installation of new computers to support the “new information system and data-processing package” can be enough to antagonize and lose the support of a considerable number of key people, who will then have to be wooed back if the system is to have any chance of success.

That said, this clinical emphasis does not mean that one can forget about the data-handling aspects of the system. The need for good-quality software and ongoing IT support should also be priorities, as these, too, are fundamental to success. After all, mayors do not feature mundane matters such as domestic water supplies when promoting their cities, but that does not mean that it doesn’t matter if the water system doesn’t work properly. It just shouldn’t be made an issue of.

### **Clarity and Realism**

All new initiatives require resources, but it is often very difficult to secure adequate funding and staffing in an arena full of multiple, competing priorities. This can lead to a heroic approach by a

team convinced of the importance of a new project and eager to get it under way at all costs. Optimistic slogans such as “The important thing is to get started,” “We’ll manage somehow,” and “Once they see the usefulness of it, it will be easier to get the money” may dominate people’s thinking and obscure the realities of the situation.

Certainly, charismatic managers may on occasion pull off remarkable feats with short-term, high-profile initiatives using this “wing and a prayer” philosophy—for example, mobilizing the good will of hundreds of professionals in dramatic drives to cut the hip replacement waiting list by 50 percent in two months or to vaccinate thousands of schoolchildren against meningitis in a week. But such an approach is much less viable for long-term projects such as RAI implementation.

Setting up a complex information system-cum-multidisciplinary clinical working method in a sector previously accustomed to neither is a big, time-consuming task, and the benefits will not be felt until it is well under way. Until clinical staff overcome cultural barriers and become familiar with the new system, they will not feel comfortable with it nor reap the rewards in their daily work; until data sets begin to span a reasonable period of time and trends can be distinguished from blips, managers and researchers cannot make full use of the data. Services and staffing ratios cannot be changed overnight even with a pile of colorful graphs to back up the case, and residents cannot be uprooted from facilities simply because data suggest it would be more rational for them to be placed elsewhere. In short, it’s a long haul, and it is important to be clear about this and about the resources that will be needed to give the project a fighting chance.

The three main tasks for which time, funding, and expertise are needed are (1) translating the instruments and manuals and keeping up with the appearance of new versions, (2) training staff in a rolling cycle of training programs that keeps up with staff turnover, and (3) developing software and instituting ongoing IT support for facilities.

Where clinical staff are concerned, be patient as they attempt to come to grips with the new system. Consider an incremental approach: although assessments are supposed to be carried out at three-month intervals, six-month intervals may be more realistic to begin with. Focusing on new admissions is another way of getting started, as is setting a specified number of evaluations to be carried out per month until, gradually, all residents have been assessed. The same goes for RAI/RAP-based care planning. Until staff become accustomed to using the table of triggers, the RAPs, and the manual, they are likely to find this very time-consuming. Expecting detailed care plans to be drawn up for all residents immediately on completion of every assessment is therefore unrealistic. Setting a more modest objective (“Attempt to write a multidisciplinary RAP-based care plan for one new resident per week”) allows staff to try out (and perhaps even enjoy!) the new system, and it enables them to gain a sense of achievement as they master the process and meet the objective. Once the process is under way, things can be stepped up. Certain tasks, however, should perhaps not be done incrementally: the sinister accumulation of boxes and boxes of completed MDS forms—with no one free to input the data and no software set up for the task—is anxiety-provoking and serves no useful purpose, so aim to introduce support software into facilities at the same time that the forms are introduced.

## **Grassroots Support**

There are advantages and disadvantages to mandating the RAI instruments. If there is no mandate, then, as Ikegami and Nishiyama comment in their case study in this report, providers cannot complain that the instrument has been imposed from above. Implementation may be difficult, but it is more “genuine.” Granted, a national government initiative mandating the use of the RAI may seem highly desirable to researchers, managers, or program coordinators battling to persuade unwilling or skeptical professionals to participate in a system whose merits they are highly convinced of. But, mandate or no mandate, clinical staff and facility managers must also be sufficiently convinced of the benefit to themselves of adopting the system, or the initiative will fail. If the system is mandated, they will of course “feed the beast” from time to time, but the arbitrary and cynical ticking of boxes that this generates is of little value to anyone and is potentially so misleading as to be dangerous.

Equally, if government mandates are being considered, it is important to be careful about what is actually mandated. If collecting MDS data is made compulsory but this new responsibility is not incorporated into the contracts of the relevant staff (with all the usual trade-union negotiations that such moves imply), this can place facility managers in an impossible situation. On the one hand, they will find themselves with a statutory obligation to send in data at regular intervals; on the other, they will have no means of obliging care staff to document their activities in such a way that MDS assessments can be accurately completed.

## **THE FUTURE**

Future strategies for addressing the issue of dependency are currently being debated in two important forums in Spain: in Parliament, via a cross-party commission, and within the framework of the Toledo Pact, a highly regarded structure that acts as a meeting point for government, trade unions, and representatives of the business community. Recommendations regarding measures to be promoted in Spain were due to be formulated by summer 2002 (although by spring 2003 they have not yet been circulated), and it seems clear that these measures should include an outline for suitable legislation to be incorporated into a new law on dependency. Taking into account experiences to date, the new legislation will have to offer some type of protection or coverage against the risk of becoming dependent that is applicable to all citizens, guarantees the constitutional principle of equal access for equal need, and, at the same time, is economically sustainable.

The new legislation will have to provide an updated conceptual framework regarding the definition of dependency and its different gradations, with special attention to a person’s ability to manage different aspects of daily life. Of particular importance in Spain is the delineation of areas of responsibility (economic and operational) in both a vertical sense (national government versus regional government versus local authorities) and a horizontal sense within any of these three levels (e.g., the finance department versus the health service versus the social services agency).

Those drawing up the legislation will also have to specify the services to be included and to define the eligibility criteria for those services, as well as to set out the means of accrediting nursing homes and other centers for dependent persons, including accreditation criteria and quality-control regulatory mechanisms. All of these things are impossible without an appropriate instrument. The RAI is a likely candidate because it fulfills a variety of functions. It confers the ability to assign users to categories requiring different levels of care and different levels of resources—a key task when determining eligibility and suitable placement—and the quality indicators can be used in conjunction with other measures for accreditation purposes (albeit only with reference to the clinical aspects of facilities).

The RAI's attractiveness also grows out of the increasing familiarity with the MDS among professionals and policymakers throughout Spain, and from the fact that it can be mounted on a range of current IT platforms and easily linked to existing clinical and administrative IT systems. The fact that the RAI system comprises a whole family of instruments allows for coverage of a wide spectrum of dependent persons in a range of settings and makes it particularly attractive to managers. Not only nursing homes but also home care, mental health care, and, with the advent of new additions to the RAI family, palliative care and assisted living facilities are all included, thus avoiding the need to learn about and implement many separate systems, each with its own criteria, coding norms, and quirks. Again, the ability to derive quality indicators from the same system has obvious appeal from a management perspective, both at the regional and the facility level.

Beyond eligibility, service allocation, and quality control, another key area is the very practical issue of financing. Spain has traditionally tended to fund almost all health care services with public money drawn from the general budget. There is very little private participation—e.g., only 7 percent of total drug expenditure—despite the fact that about 8 percent of Spain's people choose to subscribe to private health insurance as an alternative to the public provision (to which they nevertheless remain entitled). In the area of social or personal care, however, there is more of a culture of shared costs, and a problem therefore arises regarding the care of dependent persons. Often, a dependent person's condition includes a significant medical component, and this mixed situation raises questions about who should bear the costs of care. What is not in doubt, however, is the idea that protection should be universal, with no citizen left unprotected.

Universal public funding of all services for all degrees of dependency does not seem viable in the current climate of ever-rising health care costs. Given this reality, the most likely scenario is one in which full public funding will be reserved for situations of very high dependency, with the bulk of demand being covered by some mix of public and private financing. It will nevertheless be difficult to put this idea into practice, because it is unlikely that individuals will decide to take out insurance against dependency unless mechanisms are put in place that oblige them to do so. With Spain's strong tradition of state provision in health care, and given the cultural tendency to live in the present and postpone planning for the future, the average Spanish citizen is inclined to take the view that when the problem arises, if it arises, something will turn up. In this respect the government has an



important task ahead of it, although cross-party agreements, in particular if they have the support of social agencies, would facilitate matters considerably.

Spain could therefore end up with a two-stranded system of coverage: full public funding drawn from general taxation of care for persons with a very high level of dependency, and mixed funding, along the lines recommended by the Organisation for Economic Cooperation and Development (OECD), for persons with lower levels of dependency, with voluntary or obligatory private subscriptions making up the difference. Included in the category of high dependency would be those who require continuous and long-term ADL support (necessitating residential care) and/or who have concurrent chronic medical conditions. The RAI's power to help decision makers distinguish among levels of dependency is of key importance: the application of RUG-III groupings allows levels of dependency to be clearly identified in a systematic manner, separating out the high-dependency cases worthy of full public funding from the rest. Because the relative costs associated with each resident can also be defined, formulas for copayment that accurately reflect the costs incurred can be devised where required. For persons not classified as high dependency, the voluntary or obligatory insurance scheme would then come into play, bearing the corresponding proportion of the cost and making services free at the point of use for the insured.

Implicit in all the above is the fact that a law on dependency passed by the Spanish Parliament would provide a perfect opportunity to legally mandate the use of instruments allowing us to describe, plan, and manage the vast range of activities involved in caring for dependent persons. From long-term political decision making, through management and coordination of services in both the public and private sphere, right down to the day-to-day work of actually delivering care, the RAI's range of evaluation instruments offers a set of fundamental tools to aid us in this challenging area.

The system's ability to contribute to a tangible improvement in the quality of care and quality of life of dependent persons is always going to be the bottom line, and the benefits that professionals and their clients experience—whether directly or indirectly—as a result of RAI implementation will be the ultimate test of the system's utility. These benefits may come in the form of a more timely, truly needs-based allocation of services; a more sensitive and equitable set of eligibility criteria; or an improvement in the quality of day-to-day clinical care, but without such benefits the system cannot truly be said to have met its objective. We have not yet reached a point in Spain where the benefits can be assessed, but the RAI's potential to make a positive contribution is increasingly appreciated, and experiences in other countries point toward the important changes that can be brought about. For these reasons, implementation efforts continue in Spain, and we need to keep a close watch on future developments.

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## **EXECUTIVE SUMMARY**

The role of the interRAI MDS assessment system in England and Wales has developed within the evolving pattern of health and social care for older people over the past 15 years. It is clear that it will have a significant and likely growing presence and influence.

In the United Kingdom, health care is provided free to all and funded through general taxation via the National Health Service (NHS), a central government responsibility, while personal social services (or social care) are means-tested, managed, and funded (albeit predominantly through central taxation) by local government.

Current U.K. policy in health and social care of older people had its roots in policy developments in the 1980s and early 1990s. Health care provision was separated into “providers” and “purchasers” with the aim of improving efficiency and accountability for expenditure. Social services were required to be provided following a formal assessment of need.

Legislation was introduced to clarify the responsibilities of health and local authorities for provision of long-term community- and institution-based care of older people. At the same time, traditional, long-term, hospital-based geriatric medicine services were reduced. The principal criterion for determining responsibility for care was that health care should be an NHS responsibility and free at the point of delivery. By contrast, social care, which includes non-nursing support with activities of daily living, should remain the responsibility of Social Services and therefore subject to means testing, along with the “hotel” costs of long-term care. By and large the separation between health and social care became one of acute and long-term care responsibility.

The change of government in 1997 brought a further round of developments, and policy related to quality of care and more efficient use of hospital and community care, services was further refined. The government introduced mechanisms for integrating health and social care, and this was made a policy priority. Growing pressures on hospital beds focused attention on more efficient use of hospital, rehabilitation, and long-term care. Issues such as avoidable admission to and delayed discharge from hospital, appropriate settings, provision of rehabilitation, and improved assessment of need were highlighted. Services intended to provide a greater range of care between hospital, primary, and nursing home care have been developed—termed “intermediate care”—and the National Service Framework for Older People setting national standards for care of older people was published in 2001. The latter outlined a requirement for a Single Assessment Process (SAP) to provide valid, reliable, comparable assessment of need across health and social care settings. New statutory bodies have been created to regulate the standards of care and use of public resources across public, private, and independent social and health care organizations. The practical field-level requirements of the former and the information requirements of the latter provide fertile ground for the wider implementation of the Minimum Data Set (MDS) assessment systems.

With respect to community-based care, a review of currently used assessment instruments and an evaluation of the use of standardized assessment for monitoring outcomes of care both found that the

interRAI MDS system provided by far the best coverage of the domains of potential care needs and measures of performance at individual and aggregate levels. Social workers who had not had a tradition of standardized assessment felt, however, that the MDS approach risked being too lengthy, was “too clinical,” and did not record individual preferences and priorities. Lessons from this have fed into training, the government’s Single Assessment Process, and some local modification of presentation of the MDS while maintaining its integrity.

In nursing home care, the government response to the Royal Commission on Long Term Care (1999) required health authorities to pay for nursing costs in nursing homes, defined as the Registered Nurse Contribution to Care (RNCC). A project funded by the Joseph Rowntree Foundation demonstrated that Resource Utilization Groups (RUGs), which are embedded within the MDS-RAI, could reliably differentiate residents who received different amounts of registered general nursing care time.

These strands of policy and interRAI MDS assessment system research have come together in a unifying thread under the auspices of interRAI-UK, a national charity established by the Joseph Rowntree Foundation, the Norwich Union insurance company, and interRAI. The coordinating focus of interRAI-UK has supported the development of high-quality computer software and the dissemination and implementation of the MDS-RAI and MDS-HC in England and Wales. The MDS is listed in Department of Health (DoH) guidance on the Single Assessment Process and is steadily being introduced by a number of providers of community-based and long-term care. The layout and presentation of the MDS assessment forms and software have been modified in response to DoH requirements and the concerns of assessors. Forms are being actively marketed by licensed suppliers. Changes in the organization and funding of health care with an emphasis on devolving responsibility for commissioning health care to newly configured local health care organizations and new requirements for closer integration of health and social care of older people are only now settling down. “What happens next” will determine the extent of the role of the interRAI MDS assessment systems. It is already clear, however, that they will have a significant and likely growing presence and influence in England and Wales.

## **INTRODUCTION**

Writing in *The Lancet* more than 50 years ago, Marjory Warren expressed concern about the poor quality of assessment and the lack of rehabilitation of older people and stated that the key factors for successful care included individual patient assessment, patient involvement, and promoting independence (Warren 1946).

More recently, assessment has become a key part of the agenda for improving the quality of care for older people. Assessment entered the formal arena of public policy in the United Kingdom in the National Health Service and Community Care Act 1990, following the release of the white paper *Caring for People* (Cm849 1989), which made good-quality assessment and care management the cornerstones of care. The white paper viewed assessment as the key function for ensuring that

people's needs are met in the most appropriate and cost-effective manner and in the right place.

The emphasis on the importance of assessment continued through the 1990s, with the focus on multidisciplinary assessment (Department of Health 1997). Key areas identified in *The NHS Plan* (Cm4818-I 2000) were the prevention of hospitalization and excessive lengths of stay through provision of preadmission and rehabilitation care, along with the development of a unified Single Assessment Process (SAP). *The National Service Framework for Older People* (Department of Health 2001) specifically details the domains and form of the SAP, whose aims are to ensure a more standardized assessment process across all areas and agencies, to raise standards in assessment practice, and to assess older people's needs "in the round" (Department of Health 2001, paragraph 2.27).

The need to improve quality to ensure that a person receives the right response at the right time has underlain a range of reforms in the United Kingdom—and assessment is at the very heart of quality of care. This case study has three focuses: First, it briefly summarizes policy developments in the United Kingdom and, more lately, in England. Second, it discusses some of the key developments in standardized assessment based on the MDS. Third, it considers some of the processes through which national standardized assessment has been developed and looks at the potential contribution of the MDS to improved care for frail older people.

## **BACKGROUND**

In 1999 the United Kingdom's population stood at about 59.5 million, distributed through England (49.7 million), Wales (2.9 million), Scotland (5.1 million), and Northern Ireland (1.7 million). Sixteen percent of the population was aged over 64, and 3.3 percent over 84 (Office of National Statistics 2001). This represented a 5.8 percent increase in the number of those over 64 and an 18.7 percent increase in those over 84 since 1980. By 2021, the United Kingdom will have 31 percent more people over 64 than in 1999 and 40 percent more who are over 84.

The United Kingdom, through the National Health Service (NHS), provides all its citizens with free health care, funded through general taxation. Health care is a central government responsibility, while personal social services (PSS) are means-tested, managed, and funded by local governments (albeit predominantly through central taxation). In 1998-99 the total NHS expenditure was £54 billion, or approximately 6.8 percent of gross domestic product (OECD 2001). Forty percent of the current Hospital and Community Health Services expenditure is spent on people over the age of 65. Expenditure on PSS in 2001 was £10.8 billion, of which nearly half was spent on the elderly. Much of the NHS expenditure goes to hospital care, and almost two-thirds of general and acute hospital beds are used by people over the age of 65.

In common with many other industrialized nations, the United Kingdom faces increasing pressure on health care and social care services brought about by the growing population of older people. This has led the government to examine ways of improving monitoring and delivery of services to meet their needs. The past 20 years have seen many developments in health care and social

care services, and recent years have seen a range of policy initiatives that, together with the publication of the *National Service Framework for Older People* (Department of Health 2001), are intended to set the environment, core standards, and operational processes for more effective care of older people. For example, *The NHS Plan* (Cm4818-I 2000) sets out four key areas for improving services to older people (assuring standards of care, extending access to services, promoting independence in old age, and ensuring fairness in funding) as well as proposing the development of closer relationships between health care and social care. The Department of Health's *Modernising Social Services* document (Cm4169 1998) covers similar themes of independence, improved protection for vulnerable people, and the development of higher standards.

The *National Service Framework for Older People* summarizes the implementation of these changes through six related areas of activity:

- Assuring standards of care
- Extending access to services
- Ensuring fairer funding
- Developing services that promote independence
- Helping older people to stay healthy
- Developing more effective links between health care and social services and other services (such as housing) as well as partnerships between charitable organizations and the private sector

Below, we describe the evolution of these themes in long-term care policy and then identify the strands of interRAI MDS activities that relate to this process and can contribute to its improvement.

### **“Market Economy” Reforms, 1980–90**

In the late 1980s the United Kingdom implemented major reforms in both health care and community care to dramatically alter the structure and functioning of those services. In both areas, policy changes incorporated market economy aspects, although the policies themselves had separate origins.

#### **Health Care Services**

The central government in the 1980s was concerned with the pursuit of efficiency in public services, and it viewed the district health authorities as potentially inefficient providers of health care services. Health care reforms were announced in a white paper of 1989 entitled *Working for Patients* (Cm555 1989). A critical principle underlying the changes proposed in the white paper was the separation of the responsibilities of those who commissioned care (the “purchasers”) and those who provided care (the “providers”). District health authorities in England and Wales and equivalent boards in Scotland and Northern Ireland would commission from hospitals and community-based service providers the services that were required to meet the health care needs of their populations. They would become “purchasers.” General practitioners (GPs) whose patient lists and practices were larger than a certain



size would also become “purchasers” for some aspects of health care. “Provider” units (community- and hospital-based services) became self-governing “trusts,” with contractual arrangements with both district health authorities and general practices. This created an “internal market” within the National Health Service for the provision of health care.

### **Community Care Services**

During the 1980s, despite official commitment to a policy of increasing community care in people’s own homes, the rate of growth of such services declined relative to the population structure. This was because of a move to increase the involvement of the private and voluntary sectors in the provision of long-term residential and nursing home care, with funding supplied not through health or social service agencies but through the social security system. Funding was allocated purely according to financial need rather than physical need. The social security budget was not constrained in the same way that social service and health authority budgets were, so it was easier for people to be admitted to long-term institutional care than to be maintained in the community. The result was that between 1980 and 1989 there was an unprecedented explosion, from £10 million to £1 billion, in public-sector expenditures on placements in residential and nursing homes in the nonstatutory sector (Cm849 1989) and, correspondingly, that there was less pressure on health care and social service agencies to invest in community care.

Following the completion of a report by a government adviser (Griffiths 1988), the central government in 1989 published a new policy document entitled *Caring for People* (Cm849 1989). The document identified six objectives for community care services, including an explicit statement about maintaining the ability of people to live in their own homes. Formal assessment of need and case management were to be the basis for the allocation of resources and improvement in the quality of care. Social service departments became the funding organizations for community and long-term care, with the lead responsibility for assessing the needs of individuals prior to service delivery. These arrangements were fully implemented in 1993.

### **Further Reforms, 1990–2000**

With the moves to improve clarity and equity of access to health care and social care services, local health and social care authorities developed assessment systems and criteria for access that were frequently locally developed without systematic evidence for their validity or the reliability of the processes. The result was a high variability of assessment tools, which had poor comparability and little capacity to generate standardized information that could be used for the management of services at individual or aggregated levels.

In 1995, the government issued further guidance on the responsibilities for funding long-term community- and institution-based care, continuing the effort to promote home care and to help ensure

that where admission to institutional care was necessary, it would be provided by private and not-for-profit agencies rather than by the NHS or Social Services facilities (Department of Health 1995). This guidance restated the need to establish clear agreements between the health and social service authorities covering their respective responsibilities for arranging funding of care. It stressed the need for cooperation and coordination between agencies and the introduction of a good-quality, sensitive procedure for managing care arrangements in order to effectively meet individuals' needs. It also gave details of the principles to be applied in defining services, including specialist medical and nursing assessment, post-acute rehabilitation, and long-term continuing care in the hospital, people's own homes, residential homes, and nursing homes. The guidance required the setting of clear criteria for providing these services and for determining whether the NHS or Social Services would be responsible for funding them. The principal criterion for determining this responsibility was that health care should be an NHS responsibility (and therefore free at the point of delivery), while social care, including non-nursing support with activities of daily living (ADLs), should remain the responsibility of Social Services and therefore continue to be subject to means-testing, as should the "hotel" costs of long-term care.

Besides ending the contractual arrangements of the NHS's "internal market," a series of policy initiatives of the government elected in 1997 have taken the process of refining policy related to the quality of care and the more efficient use of hospital and community care services a step further. As demand for hospital beds has mounted, attention has increasingly focused on the efficient use of hospital, rehabilitation, and long-term care resources. This focus has highlighted issues such as avoidable hospital admissions and delayed discharges as well as that of determining the appropriate settings for assessment for and provision of rehabilitation.

The government has also created incentives to promote closer links between health and social services, giving them a new ability to pool budgets and to share the development and management of services for older people. New styles of service, termed *intermediate care*, between, on the one hand, primary health care at home, and, on the other, secondary health care in hospitals, community support services, and long-term institutional care have also been developed. Intermediate care services meet all the following criteria:

- They are targeted at people who would otherwise face unnecessarily prolonged hospital stays or inappropriate admission to acute inpatient care facilities, long-term residential care facilities, or NHS inpatient continuing care facilities.
- They are provided on the basis of a comprehensive assessment, resulting in a structured individual care plan that involves active therapy, treatment, or opportunity for recovery.
- They have a planned outcome of maximizing independence and, typically, enabling patients/users to resume living at home.
- They are time-limited, normally running no longer than six weeks and frequently as little as one or two weeks or less.
- They are provided by cross-professional teams using a single assessment framework, a single set of professional records, and shared protocols.

The government has also provided clarification of responsibilities for funding the health (NHS) component of long-term institutional care, committing itself to developing means for determining which aspects of continuing care require the professional skills of registered nurses (the Registered Nurse Contribution to Care, or RNCC; see below). The key policy documents associated with these initiatives are *The NHS Plan* (Cm4818-I 2000) and *Modernising Social Services* (Cm4169 1998).

The most recent part of these policy developments is covered in the *National Service Framework for Older People* (Department of Health 2001). This document, the fourth in a series of National Service Frameworks (NSFs) for health care services, sets standards to be met in providing older people with services in eight areas (rooting out age discrimination, person-centered care, intermediate care, general hospital care, strokes, falls, mental health, and health promotion). A core component of the standard for person-centered care is the requirement for a Single Assessment Process (SAP). The aim of the SAP is to ensure that

- A more standardized assessment process is in place across all areas and agencies.
- Standards of assessment practice are raised.
- Older people's needs are assessed in a comprehensive manner.

Demand for a more standardized approach to assessment arose from the evident variability of the assessment process in practice (Stewart et al. 1999) and the need to develop more equitable, effective, and efficient services. Since so much of the modernization process in community-based and long-term care hinges on the provision of the right care in the right place at the right time, the family of MDS-based assessment instruments has a potentially important contribution to make.

## **THE MDS INSTRUMENTS AND U.K. HEALTH POLICY**

Research indicates that the MDS can make a major difference in four theme areas that are central to policy implementation: the need for a standard approach to community-based assessment, assessment in long-term care and its relationship with quality assurance, effective estimation of resource use, and the relationship of the Single Assessment Process to the allocation and reimbursement of the Registered Nurse Contribution to Care in long-term care settings.

### **Theme 1: Assessment in the Community**

An analysis of assessment instruments in use in the United Kingdom (Challis et al. 1996; Stewart et al. 1999) highlighted the wide variation in assessment practices, including the widespread omission of important domains and the lack of comparability and standardization. In 1997 the Department of Health commissioned a series of research and development projects under the general banner of Outcomes of Social Care for Adults. One of the projects was a study that tested the routine use of standardized assessment for measuring the outcomes of social care. This two-year, randomized, controlled trial compared the use of the Minimum Data Set Home Care (MDS-HC) by social workers

in their everyday practice as opposed to that of the current care assessment (CCA) they ordinarily used in their work. A total of 420 people, 210 in each of two Social Services Departments (SSD1 and SSD2), were randomized to assessment by social workers using the MDS-HC or their CCA.

The study found that social workers' responses to the MDS-HC depended on the organization of the social services department. In SSD1 the CCA was nonstandardized and was completed largely using free text. These social workers were less happy using the MDS-HC than those in SSD2, whose CCA was much more structured. Forty-five to 55 percent of outcome items were missing from SSD1's CCA, while only 15 to 35 percent were missing from the CCA used by SSD2. This compared with less than 5 percent of items missing from the MDS-HC assessments. Aggregated outcome scales for ADLs, instrumental activities of daily living (IADLs; including activities such as housework, cooking meals, and using transportation), and cognitive function scales could be completed for fewer than half of the CCAs in SSD1, for 45 to 95 percent of the CCAs in SSD2, and for more than 95 percent in MDS-HC assessments. When free-text assessment records were coded in the SSD1's CCAs, the results suggested that some problems were likely being missed because their incidence appeared to be lower in the CCA assessments than in the MDS-HC assessments. If a problem was identified in a CCA reassessment but there had been no record of that problem's presence or absence in the initial assessment, one could not know whether the problem was truly absent at the initial assessment or it simply had not been recorded.

The study also compared the outcome scales of the MDS-HC and the CCAs against established gold-standard assessment instruments for particular domains, including physical and cognitive function and depression. The outcome scales of the MDS-HC correlated well with those of the gold-standard instruments, with the exception of the depression scale, where the correlation was less strong. An evaluation of the MDS-HC and the CCAs against nine criteria for determining the ability of the instruments to measure outcomes of social care found that the SSD1's CCA met no test criteria; the SSD2's CCA met three; and the MDS-HC met eight. These criteria were as follows:

- Can the assessment data be computerized?
- Are the outcome indicators present in the assessment?
- Are the outcome indicators valid and reliable?
- Can the assessment instrument monitor change in a population over time?
- Can the assessment instrument monitor change in individuals over time?
- Can the assessment instrument identify different subpopulations?
- Can the assessment instrument produce timely information?
- Is information showing change or outcome readily available to assessors and managers?
- Is the assessment instrument usable by assessors?

The MDS-HC demonstrated important benefits of standardized assessment. It included valid, informative outcome scales; could compare populations over time; and showed changes in individuals over time as well as the impact of those changes on informal caregivers. The MDS-HC level of care case-mix system based on MI-Choice algorithm (Fries et al. 2002) gave clear information at a macro

level on the differences in outcome among people with differing levels of disability. The MDS-HC also demonstrated clear relationships between client characteristics, the services provided, and the burden on informal caregivers. These would be helpful in providing assessment-related criteria for eligibility for different levels of service provision.

Interviews with the social workers suggested that, overall, structured assessment forms were preferred but that they also wanted to be able to include free-text descriptions in their assessments. All the social workers found the MDS-HC to be health-oriented, but those from SSD2 were more positive about the inclusion of health items in the social care assessment. Generally, the social workers thought that nearly all the areas covered in the MDS-HC were relevant to community care, although there was no agreement on which areas were not. There seemed to be little difference between the time it took to complete an MDS-HC assessment and that required to complete the CCA, although assessors did complain that it seemed to take too long to complete the MDS-HC. The social workers saw that they explored more areas using the MDS-HC and that the resulting assessment interview was a more formal process, but some voiced concern that using the standardized responses alone did not produce a reliable record of needs and that the resulting assessments were difficult to interpret. Many also wanted to be able to omit sections that were clearly not relevant to the clients they were assessing.

The study's findings carried some clear messages regarding the MDS-HC's adoption. Some items, because of their medical nature, were difficult for social workers to complete. Social workers wanted the ability to do some free-text assessment, which would allow them more flexibility in describing clients' and informal caregivers' circumstances, feelings, and preferences. Despite these drawbacks, however, the study revealed that social workers found little about the MDS-HC that was irrelevant and little that was missing. And, despite the fact that social workers, on first seeing the MDS-HC, often thought that it would take too long to complete, the study did not show this to be a major problem.

Though social workers in SSD1 expressed concern that the structured responses to the assessment items might not give a reliable picture of the client, the correlation of responses to the MDS-HC with the responses to the gold-standard instruments suggests that this was not so. The social workers' anxiety about this may have been due to the fact that they were unaccustomed to using standardized assessment items, a conclusion reinforced by the fact that these anxieties were less frequently reported in SSD2, where the CCA contains some standardized items.

The view that the MDS-HC was too "health-oriented" needs exploration. Because the MDS-HC is designed to identify difficulties and to recommend intervention to remedy underlying problems or to provide support where these cannot be remedied, an important social care element may be missing. This factor has to do with the relationship between the client's disability (resulting from chronic, nonremediable conditions) and compensatory care responses. After all, social care needs may be defined as "need shortfalls," and one of the focuses of social care is to close the gap between needs resulting from nonremediable disability and the existing support for those needs (e.g., the current compensatory inputs of agencies and family caregivers). Effective assessment for long-term community-based care must evaluate three interlocking systems: the individual person, the informal

care system (including the family), and the formal care system. The study showed that the MDS was most effective in evaluating the first of these and could tackle the second to some extent, but did not record specifically the *shortfall* between formal services and nonremediable disability.

Some social workers found it difficult to get a clear overall picture of their clients from the MDS-HC assessment forms used in the study. They all found the form easier to use with practice and would likely find it easier to interpret if the layout of the form were improved and with more experience in its use. Some saw the MDS as overly structured and not “person-centered” enough to allow nuanced responses reflecting the feelings and preferences of the person being assessed. This appears to be a factor in social workers’ resistance to adopting the instrument. It is a matter of debate, however, whether this might not be a simple issue of training, which would enable staff to clearly separate the content of assessment from the form or style in which information is gathered. A further factor behind social workers’ resistance may be that at the time of the study social workers throughout the United Kingdom felt burdened by workload, by funding constraints, and by the rapidly evolving policy changes. (These pressures are still affecting the profession today.)

## **Theme 2: Assessment in Long-Term Care Settings**

In the early 1990s, the assessment of long-term care settings had not yet received much attention in the United Kingdom. In 1995, the Joseph Rowntree Foundation commissioned a study to examine approaches to assessment that could form the basis of a national standard instrument for nursing and residential homes for older people. The requirements for such an instrument included the following:

- It should be usable and acceptable on a national basis yet permit some local variation.
- It should be approved and recognized by both the health care and the social service professions.
- It should value and encourage the independence of the user (i.e., the person assessed).
- It should “weight” the characteristics of an individual assessed by the system so as to identify the particular skill mix needed for that person’s care and the costs of providing care staff.
- It should place a value on the individual’s personal needs and take broader social care needs, not just physical care, into account.
- It should be applicable to a range of settings, from residential homes to full nursing care and hospital settings.
- It should have the potential to be incorporated into a computer software package.
- It should be comprehensive and have easily understood guidelines for implementation.

The study produced a published monograph (Challis et al. 1996) that proved of great interest to a very wide audience. It reviewed the role of assessment and looked at a number of key issues in long-term care, including the prevalence of problems in residential and nursing homes, quality assurance, indicators of outcome and quality of life, and the importance of rehabilitation beyond hospital care. The review of assessment approaches and their use in other countries led to a detailed analysis of the origins, content, and potential use of the Minimum Data Set/Resident Assessment Instrument

(MDS/RAI). The monograph's concluding recommendation that the MDS/RAI should be further evaluated in the United Kingdom was based on the fact that it had been developed according to scientific principles, that it contained standardized assessment items and links to care planning, and that it was integrated with the Resource Utilization Group (RUG) case-mix system (Fries et al. 1994).

A follow-up study for the Joseph Rowntree Foundation examined the MDS/RAI's training requirements and its acceptability to nursing and residential home care staff. The study determined the minimum training and follow-up requirements for implementation and suggested that a reasonable and satisfactory approach would consist of one training day with a follow-up session two weeks later to discuss experience in use. This recommendation was incorporated into the *UK Long Term Resident Assessment Instrument Manual* (MDS/RAI UK; see Challis et al. 2000).

A number of nursing home providers have field-tested the MDS/RAI. Effective training and follow-up assistance have been critical to such projects. One major chain found that the anxieties about and criticisms of the instrument encountered in the early stages of its study were replaced by manifest enthusiasm following the training, and that staff were then disappointed when the "experimental" use of the MDS ended and they had to return to older, less satisfactory methods. The chain's managers generally thought that the project had been very successful and felt that the MDS/RAI would be of great benefit for assessing residents, examining case mixes, and improving care-planning procedures in their homes.

### **Theme 3: Measuring the Cost of Care**

With the development of the internal market, contracts for care and costing of care became important issues. Specific attempts were made, primarily with regard to hospital-based services, to develop case-mix measures that could be used for costing. In the early 1990s, the National Casemix Office (NCMO) embarked on a research and development program to produce a resource-use case-mix grouping system for use in the development of contracts for hospital care. The American Diagnosis Related Groups (DRGs) system was considered the best starting point for this exercise. After a preliminary examination of DRGs, the NCMO began consultation exercises with the medical profession to explore the potential for adopting DRGs for use in the United Kingdom, albeit with some modifications to accommodate U.K. practice. At a meeting of the Royal College of Physicians in London, the NCMO presented DRGs for medical services to a group including specialists in geriatric medicine. The response of the geriatricians was that diagnosis, procedure, age, and gender could not usefully predict hospital lengths of stay of older people. For this reason, a working group under the leadership of Iain Carpenter formed to explore alternatives that would be more relevant than DRGs to older hospital inpatients with nonsurgical conditions.

The working group first examined a variety of acuity systems that were currently in use and found that Resource Utilization Groups (RUGs) seemed to be an effective and useful way of classifying elderly patients who require more than just acute medical care. The working group saw that the RUGs

provided a common language in an area where such a language was much needed but had been difficult to develop. The group felt that the RUGs could help direct resources (whether staffing or cash) appropriately. It recommended to the National Casemix Office that

- The RUG classification system be examined in detail and that it should be seen in practice
- The progress and final report of the Dutch RUG validation project should be examined
- A RUG evaluation project should be considered in the United Kingdom

As a consequence, the NCMO commissioned a study to validate RUGs in the United Kingdom. The project involved the assessment of 2,000 patients in 29 hospitals distributed through six health districts in England and Wales. During the course of the study many nursing and therapy staff expressed concern that they were being subjected to time-and-motion studies that might affect their employment and that a system as objective as the RUGs—with assessment items confined to tick boxes and numbers—could not truly define the care time requirements of older people. The study confirmed, however, that the RUGs did indeed explain variations in the allotment of nursing time in the care of elderly patients in acute rehabilitation and long-stay wards and that it could therefore form the basis for a resource-use case-mix system (Carpenter et al. 1995).

A number of issues had to be addressed, however, before the RUGs could be considered usable in these settings. These issues included

- Establishing that nursing staff could reasonably complete the RUG questionnaire for hospital patients on a routine basis
- Devising the system in such a way that the per diem cost of care, which is the basis of the RUGs, could be used to calculate the cost of an episode of care
- Determining if and how the RUGs could be widely implemented

A second study, conducted in three hospitals, found that fortnightly RUG assessments would give a reasonable picture of the cost of care time for an inpatient over a whole episode. The study also proposed a way in which the RUGs could be used for costing contracts for care with purchasers (Carpenter et al. 1997).

The change in government in 1997, however, brought with it a commitment to end the purchaser-provider, “free market” system of contracting for hospital services, and consequently the costing of care on the basis of case-mix systems such as the RUGs was moved to a back burner.

More recently, the use of the RUGs (in the form of the Resource Utilization Groups, Version III, or RUG-III) has reemerged in policy discussion, with the development of the reimbursement of the Registered Nursing Care Contribution of people admitted to nursing homes in England. A project funded by the Joseph Rowntree Foundation demonstrated a simple reimbursement model for these people, matching the three levels of care identified by the Department of Health—high, medium, and low (see below)—to reimbursement levels.



#### **Theme 4: Recent Policy Developments**

The MDS assessment method has contributed to Department of Health policy development in two specific areas: the development of the Single Assessment Process (SAP) as recommended in the *National Service Framework for Older People* (Department of Health 2001) and the development of a means of determining an appropriate level of reimbursement for the Registered Nursing Care Contribution to care of people admitted to nursing homes.

#### **The MDS-HC and the Single Assessment Process**

The Department of Health (DoH) established a national assessment working group (NAWG) to advise on policy guidelines for the SAP. The NAWG was unable to identify any existing assessment tool that adequately covered all the domains and subdomains specified for the SAP in the *National Service Framework for Older People* that was sufficiently person-centered and that met other requirements. The DoH did, however, specify criteria that had to be met by any SAP and also specified a series of steps to be followed by local agencies in coming to an agreement on an SAP for local use. In addition, the department specified levels of assessment and developed rigorous criteria against which local agencies should evaluate current or proposed approaches to assessment in order to help them identify changes they might need to make to ensure that their assessment systems would comply with DoH requirements. The specified levels of assessment were as follows:

- Contact assessment (including the collection of basic personal information), which would cover the basic details of a presenting problem, which might be simple and require no further action other than providing treatment for the specific problem. To be included in this assessment were the nature and duration of the problem, the importance of the problem to the person assessed, and a brief exploration of whether there were any other issues or recent life-events that might be relevant, including the views of caregivers.
- Overview assessment, which would cover a broad range of domains, though not necessarily all the domains that would be expected in an in-depth or comprehensive assessment
- In-depth assessment, which would cover all the NSF domains and could be used for developing adequate care plans for people who would be able to manage in their own homes with appropriate treatment and support
- Comprehensive old age assessment, which would be essential for all old people likely to be admitted to nursing or residential care homes

The key attributes of the SAP as specified in the guidance were as follows:

- A person-centered approach in which the older person seeking care would experience a single assessment process—one in which information about problems would be given only once, professionals would work together in the best interests of the older person, the older person's views and wishes would be central to the assessment process, the assessment would build a well-

- rounded picture of the person's problems and circumstances, and the depth and detail of the assessment would be proportionate to the person's needs
- A standardized approach that would be supported by an agreed-on evidence base; would build on good practice; would be useful to practitioners; would enable professionals to see, trust, and accept one another; would produce standardized information in a single summary record; would facilitate the sharing of this case information among professionals; and would generate information for strategic planning and performance monitoring
  - An outcome-centered approach that would evaluate assessment information and translate it into appropriate and effective care plans and services; would allow for monitoring of change with respect to the older person's health, independence, and quality of life; and would identify the person's potential for rehabilitation

In addition, the DoH provided extensive guidance on joint working arrangements, information requirements, and staff development.

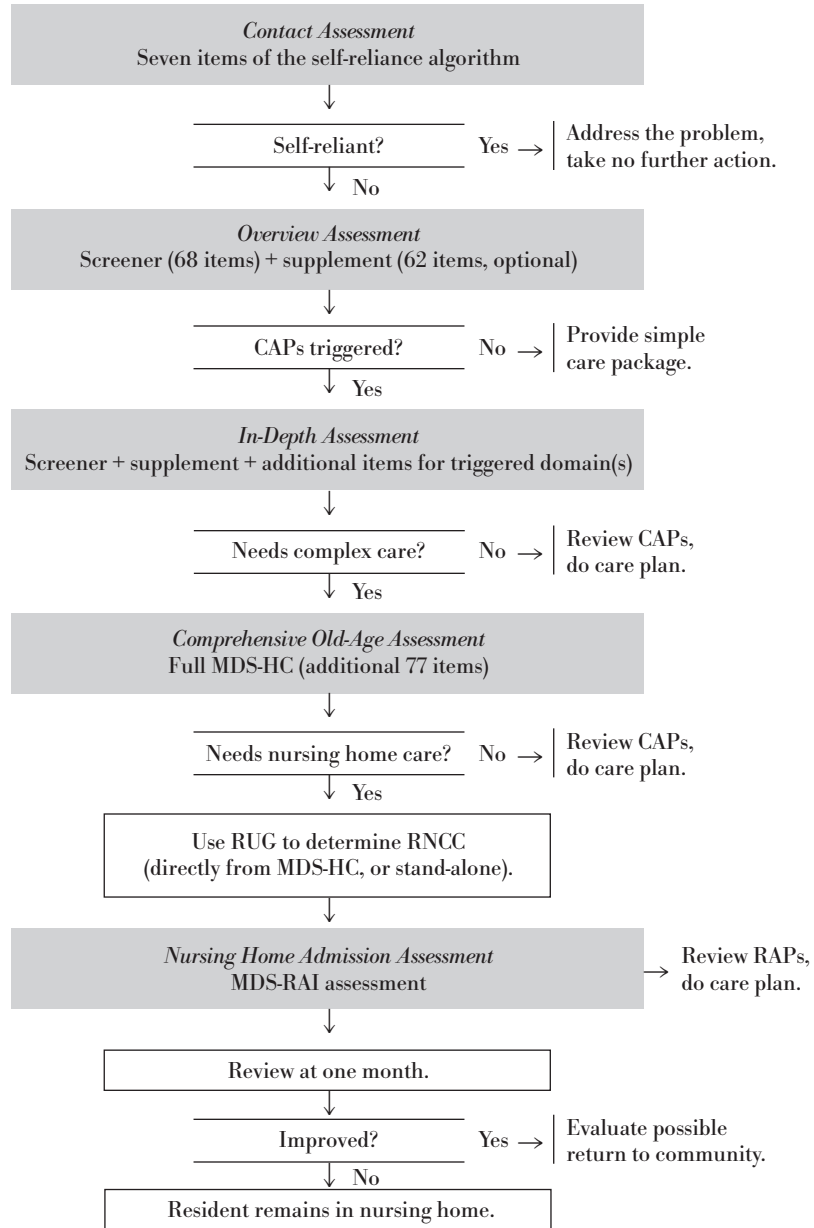
NAWG reviews of summary descriptions of the instruments are posted on the Department of Health's Web site (<http://www.doh.gov.uk/scg/sap/toolsandscales>). Each instrument has some recommended characteristics. Many aspects of the guidance directly correspond to and have a great deal in common with the MDS-HC, and the guidance recapitulates characteristics required of the SAP. The principal perceived weaknesses of the MDS-HC have to do with its apparent lack of sensitivity to biographical detail and to the preferences and feelings of the people being assessed. The need to know how people feel about the difficulties that they face—and the need to accurately record what those difficulties are—is the core difference between the “social care” and “medical” models of assessment, care planning, and care delivery. This difference was evidenced in the MDS-HC study described above and remains an incompletely resolved tension in the development of the Single Assessment Process. Because the champions of the various recommended instruments will address these key factors, it is likely that within the next few years there will be a significant convergence of assessment instrument characteristics.

Between 1998 and 2001, *interRAI* used its extensive assessment database to explore evidence-based methods of identifying the key components of the MDS-HC that could be used for screening and relating assessment to eligibility for different levels of community care. These efforts, conducted primarily at the Hebrew Rehabilitation Center for the Aged in Boston and at the University of Michigan, produced a self-reliance algorithm, a screener, and a screener supplement that have a statistical basis.

Proponents of the MDS believe that the specified levels of assessment in the SAP can be broadly matched to the MDS system by using the self-reliance and MI-Choice level-of-care algorithms for contact and overview assessments, the MDS screener for the overview assessment, the screener and supplement for the in-depth assessment, and the full MDS-HC (with the subsequent referrals and actions) for the comprehensive assessment. The triggering linkages between these MDS algorithms permit logical links between the levels although local contextual work is required to further validate these (Figure 1).

**FIGURE 1. MDS ASSESSMENT LOGIC COMPARED WITH THE SAP**

Note: At any time the assessor may go directly to a comprehensive old-age assessment if professional judgment so indicates.



## **Determination of the Registered Nurse Care Contribution to Long-Term Care**

The Royal Commission on Long Term Care, whose formation had been announced in December 1997, reported its findings in March 1999 (Cm4192-I), recommending that the full costs of nursing home care should be funded out of general taxation. The report triggered a national debate on the ethical, moral, and financial aspects of funding long-term care of older people. As a result, different policies emerged in different part of the United Kingdom. Scotland accepted the commission's recommendations, but in England, the Department of Health decided that while the health care component (defined as that care requiring registered nursing care) should be funded, the social care component ("hotel" costs and assistance with activities of daily living) should remain a means-tested benefit.

A group within the Department of Health has been addressing the difficult task of identifying those characteristics of people being admitted to nursing homes that require the attention of a registered nurse—that is, the Registered Nurse Care Contribution (RNCC). Appropriate RNCC reimbursement should be determinable from information obtained in the final stages of the Single Assessment Process immediately prior to admission to a home, with reviews to be conducted at three months and annually thereafter, or when there is a significant change in the resident's condition.

The Joseph Rowntree Foundation commissioned a study, conducted in four nursing homes in England, to determine whether components of the MDS assessment system could be used for this task. The study found that the amount of time spent on direct (hands-on) care and indirect care (care planning, discussion with professionals and relatives) was very different for residents in specific clinical groups in the MDS-based RUG-III case-mix system. There were also large differences between the time provided to residents by registered nurses and by care assistants. The study identified three groups of residents: those with complex problems who were receiving significant care from registered nurses, a larger group (sharing common characteristics) that appeared to receive a basic level of nursing care, and a group that appeared to have minimal requirements for registered nurse care (Carpenter and Perry 2002). DoH cited this research during consultations that led to the recommendation that the reimbursement system categorize residents into three groups: those with high, medium, and low levels of need. The recommended reimbursement for each of these levels directly reflects the time identified in the Rowntree Foundation-funded study. Ongoing work at the University of Kent and the University of Northumbria is further exploring the relationship between the RNCC and the RUG-III system.

### **RECENT POLICY DEVELOPMENTS AND THE MDS**

To what extent, then, might the MDS family of instruments contribute to these policy developments, particularly with respect to the Single Assessment Process? In answering this question, it is helpful to look at the broader literature of interagency and professional collaboration for some pointers, since the successful implementation of the Single Assessment Process will largely depend on how well agencies and professionals coordinate their work.

Coordination and collaboration between health care and social service agencies are difficult to achieve and therefore matters of longstanding concern. Coordination is, however, critical to achieving greater rationality in the provision of care, and the introduction of standardized assessment aims at increasing such coordination. The turbulence of the institutional environment and the relative uncertainty that exists during a period of change—particularly about the roles of staff—can greatly affect the success of an implementation. It is likely that externally mandated interrelationships, such as that required by present policies for health and social care services, can make coordination and collaboration both desirable and rational. Exchange relationships and reliance on shared resources can also induce collaboration (Schmidt and Kochan 1977). Where established organizational practices are in place (and where there is a tradition of inertia), imposing an externally developed form of assessment may be a more acceptable approach to change than trying to reshape existing processes from within.

In the current context, the mandate to implement the SAP, the potential for mutual benefits, and even the uncertainty of the situation all create opportunities for agencies to coordinate their efforts and for professionals to form exchange relationships. On the other hand, it remains to be seen whether trust between professionals—a key ingredient of collaboration—is sufficient for success. Furthermore, it is unclear whether turf battles—for example, over who controls which domains of assessment—will occur or how serious this “domain defensiveness” (Challis et al. 1988) might be, and thus whether it might lead to the reassertion of older defined boundaries. Levine and White (1961) suggest that effective implementation requires domain consensus over areas of responsibility and therefore considerable agreement among professionals on their respective roles (see also Van de Ven 1976). The guidance on the Single Assessment Process issued by the Department of Health specifies 12 steps that should be taken in preparing for implementation, eight of them having to do with staffing and service interrelationships.

Can assessment instruments help prevent territorial issues from arising, permit the negotiation of new roles, and contribute to the building of new exchange relationships and trust in an environment where change is mandated? This question is of real importance. It must be remembered that these instruments are new to practitioners, and that practitioners’ perceptions regarding the unfamiliarity and complexity of some instruments, and perhaps the MDS in particular, risks derailing the very real benefits that should follow from the introduction of the Single Assessment Process.

Proponents of the system regard the MDS instruments as tools that can link assessment for hospital care, community-based care, and nursing home care. The MDS approach could ensure that assessment is uniform, that its core content is transferable across settings and agencies, and that assessment accurately and appropriately identifies needs. The built-in links to care planning and the integral scales and algorithms make available aggregated patient and service outcome information that can contribute to the monitoring of care standards, outcomes, and funding allocations across agencies. Certainly, a range of stakeholders could benefit from the widespread implementation of the MDS approach. The information generated could contribute to performance monitoring at a national level. It could provide the basis for more detailed standards against which regulators could monitor services. At the agency level, the data could be used for better resource allocation and more effective

management strategies, while at a sub-unit level, such as a community-based team, the information could contribute to enhancing practice, local monitoring, and quality.

One interesting development has been the establishment of *interRAI-UK* as a national charity to facilitate research, dissemination, and implementation of the MDS system. The group represents a pragmatic confederation between Norwich Union, a large insurance company with concerns about the effective allocation of long-term care insurance resources; the Joseph Rowntree Foundation, a charity with a long track record of supporting research and development in the long-term care of older people; and researchers with concerns for the development of long-term care policy and practice. The overlap of interests is remarkable and offers an interesting model for the development of long-term care assessment. *interRAI-UK* aims to support the continuing development of the components of the MDS system, as well as training, information technology implementation, and data analysis, to ensure that the instruments meet policy requirements as these mature over time.

The introduction of more standardized approaches to assessment represents a major change of direction for local health care and social service agencies in the United Kingdom. This change is, of course, entirely congruent with the general pursuit of practice that is more evidence-based. It is likely that as policy and practice develop in the United Kingdom, the MDS will be one of a number of assessment instruments in use. If the benefits are to be greater than the costs of using these instruments, there will need to be a regime of continuous improvement both in the instruments themselves and in the ways that information from them is employed. Practitioners will continue to use the instruments only if they derive benefits from them, both in their day-to-day work with older people and in their broader decision making based on information derived from the aggregated assessments. Similarly, managers will be able to persuade their staffs to use the instruments only if they can provide them with evidence of better practice and enhanced information. The significant challenge is to ensure that the needs of all the users of standardized assessment, at all organizational levels, are met so as to provide them with the appropriate incentives for their continued use.

Finally, why have we titled this study “A Thread from Many Strands”? The research literature on the care of older people has consistently shown the importance of assessment, and better assessment is the underlying theme that links the policy strands that we have described in this paper. It seems that the Single Assessment Process could be the thread that will be woven from these strands, and the MDS assessment system can make a major contribution to each. We must be cautious, though. This thread, though it may get woven, may also unravel. The rate and scale of change in U.K. policy, as described in the postscript, below, could prove its undoing.

#### **POSTSCRIPT**

Developments in U.K. policy on assessment and long-term care continue apace. The structure of the NHS changed dramatically in April 2002 with the removal of local and regional executive layers. There are now fewer health authorities, and newly created Primary Care Trusts (PCTs) have a pivotal role.

The PCTs are intended to be the cornerstone of the NHS, providing the vital links between the NHS executive and GP practices and coordinating the demand for and supply of acute hospital services. They are responsible for the health of the people in their areas, bringing health and social care closer together and developing integrated services for patients. By 2004 the PCTs will control 75 percent of the total NHS budget, with the aim of ensuring that resources meet local needs. They will undertake many of the functions previously exercised by health authorities—for example, commissioning health services and investing in primary and community care. The PCTs will ultimately have the responsibility for implementing the Single Assessment Process.

The Commission for Health Improvement, established in 2000, is currently the major NHS regulatory authority. Its aim is to improve the quality of patient care in the NHS and to raise standards by

- Assessing every NHS organization and making the findings public
- Investigating whenever there is a serious failure
- Checking that the NHS is following national guidelines

The National Care Standards Commission, established on April 1, 2002, is responsible for regulating social care and independent health care services in accordance with statutory regulations and national minimum standards issued by the Department of Health.

On April 17, 2002, the Department of Health announced that these two organizations are to be disbanded. Instead, there will be two new independent inspectorates: the Commission for Social Care Inspection and the Commission for Healthcare Audit and Inspection.

The work of the Commission for Social Care Inspection (CSCI) will encompass that of the former Social Services Inspectorate (which assisted ministers in carrying out their responsibilities for personal social services and exercised statutory powers on behalf of the Secretary of State for Health) as well as substantial responsibilities that had belonged to the National Care Standards Commission. CSCI will have responsibility for the inspection of all social care organizations—public, private, and voluntary—as well as all local-authority social service departments.

The Commission for Healthcare Audit and Inspection (CHAI) will bring together the functions of the Audit Commission (which was responsible for ensuring that public money was used economically, efficiently, and effectively) with the private and voluntary health care role of the National Care Standards Commission and the work of the Commission for Health Improvement. This new body will be responsible for inspecting both the public and independent health care sectors and for explaining to the public how resources have been deployed and the impact that these resources have on improving services and raising standards.

The process of establishing the PCTs is consuming the energies of health and social care managers, and social service departments appear to be bearing the brunt of the implementation of the new assessment procedures. The establishment of the Commission for Social Care Inspection and the Commission for Healthcare Audit and Inspection represents another stage in the changing relationship between health care and social care in the United Kingdom.

Most recently, the relationships between the central government and the public sector at large appear to be changing, with moves to reduce the extent of central control. These developments and changes will continue to have a major impact on what happens next in the United Kingdom with respect to assessment and performance monitoring.

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## THE AUTHORS

### INTRODUCTION

Brant E. Fries, PhD, is a Professor of Health Management and Policy at the University of Michigan School of Public Health and founder and President of *interRAI*. A health services researcher, he focuses on the use of large-scale databases of assessments for designing practical assessment, payment and regulatory systems, and setting long-term care policy.

Msgr. Charles J. Fahey, Marie Ward Doty Professor Emeritus from Fordham University, is a program officer for the Milbank Memorial Fund. As a Roman Catholic priest in the diocese of Syracuse, New York, he served in Catholic Charities there and at Fordham University's Third Age Center. He has held many national and international posts. He chaired the federal Council on Aging during the Carter administration and was a leader of three White House Conferences on Aging and two United Nations World Assemblies on Aging. He has been president of Catholic Charities USA, the American Society on Aging, and the American Association of Homes and Services for the Aging.

### UNITED STATES

Catherine Hawes, PhD, is Professor of Health Policy and Management and Director of the Southwest Rural Health Research Center at the School of Rural Public Health at the Texas A&M University System Health Science Center. Her research has focused on quality assurance on long-term care, with a particular emphasis on nursing home quality, studies of assisted living and residential care facilities, and the effects of regulation on quality. She also served on the Institute of Medicine Committee on Nursing Home Regulation.

Bruce C. Vladeck, PhD, is Senior Vice President for Policy and Professor of Geriatrics and Health Policy at Mount Sinai Medical Center in New York. From 1993 through 1997, he was Administrator of the Health Care Financing Administration. The author of *Unloving Care: The Nursing Home Tragedy* (1980), he served on the Institute of Medicine Committee on Nursing Home Regulation, whose recommendations led to the OBRA '87 nursing home reforms.

John N. Morris, PhD, is the Co-Director of HRCA Research and Training Institute of the Hebrew Rehabilitation Center for the Aged (Boston) and Director of Social and Health Policy Research. He has been endowed the Alfred A. and Gilda Slifka Chair in Social Gerontological Research at HRCA, the nation's first faculty chair in social gerontological research. Morris has been at HRCA for more than 30 years, and during that time he has participated in a wide variety of federally funded long-term care studies. Over the last few years he has received funding for studies looking at issues of vulnerable elderly in the community, on the path to institutional placement, and in the nursing home. Grant and contract support has come from HCFA, AHCPR, ASPE, NIA, and NINR.

Charles D. Phillips, PhD, MPH, is Professor of Health Policy and Management and the Director of the Health Services Research Program at the School of Rural Public Health at the Texas A&M University System Health Science Center. His research and teaching interests are in health services

research and in gerontology. His work in gerontology focuses on measuring quality of care and understanding the effects of innovations aimed at enhancing quality of life in residential settings. He has received funding from a number of federal agencies and foundations. He currently serves on the editorial board of *The Gerontologist*.

Helene Fredeking, BA, MEd, recently retired from the U.S. Department of Health and Human Services. During her federal service she was the manager within the Health Care Financing Administration who had direct responsibility for the development and implementation of an assessment instrument that was required to be used by all Medicare and Medicaid-certified nursing homes in assessing the care needs of all residents. She also led in the establishment of a national database of assessment information on all residents in nursing homes. Other responsibilities included the development of the survey and certification process for nursing homes as required by the nursing home reform provisions of OBRA '87.

#### **CANADA**

John P. Hirdes is a professor in the Department of Health Studies and Gerontology at the University of Waterloo and Scientific Director at the Homewood Research Institute in Guelph. He holds a Canadian Institutes for Health Research (CIHR) Investigator Award in Health and Aging, and is a Fellow and board member of *interRAI*. His current research interests include health information management, international comparisons, assessment systems, funding, quality, outcomes research, and health service utilization.

Duncan G. Sinclair, presently Professor Emeritus of Physiology and Visiting Fellow in the School of Policy Studies of Queen's University, retired in 1996 as Vice-Principal (Health Sciences) and Dean of Medicine at Queen's. He had served previously in a number of senior administrative roles including Vice-Principal (Institutional Relations), Vice-Principal (Services), and Dean of Arts and Science. He chaired Ontario's Health Services Restructuring Commission from 1996 to its sunset in 2000 and served as founding chair and acting CEO of Canada Health Infoway/Inforoute Santé du Canada from January to June 2001.

John King has been Executive Vice President for hospital services at St. Michael's Hospital in Toronto since July 2002. He is a certified health executive with 20 years of experience in the health care field, chiefly in the western provinces. He was the Alberta director on the board of Canadian College of Health Service Executives as well as Senior Vice-President of the Alberta Healthcare Association and Senior Operating Officer of several Alberta hospitals under the umbrella of the Calgary Regional Health Authority. From May 1999 to June 2002, the period during which this case study was written, he was the Assistant Deputy Minister for Health Care Programs in the Ontario Ministry of Health and Long-Term Care.

Paul Tuttle is Director of Long-Term Care Facilities in the Health Care Programs Division of the Ontario Ministry of Health and Long-Term Care. He has been with the ministry since 1990, previously

as a Policy Analyst in Community Services. Prior to joining the ministry, he was the Executive Director of Durham Region Community Care Association. He was also the founding President of the Ontario Home Support Association (now a part of OCSA). He has worked at the Canadian Mental Health Association and the Canadian National Institute for the Blind, and has served as a member of various community boards.

John McKinley is Executive Director of the Health Care Programs Branch of the Ontario Ministry of Health and Long-Term Care. He is responsible for long-term care facilities, community care access centers and children's treatment centers, and finance and information management of the Health Care Programs Division. He came to this position from his role as Director of the Finance and Information Management Branch. He has extensive experience in the ministry in a variety of operational, policy, and financial positions that crossed many program areas. He studied business administration at the University of Ottawa, where he graduated in 1985.

#### **ICELAND**

Pálmi V. Jónsson is Chief of Geriatrics at Landspítali-University Hospital in Reykjavík and an Associate Professor of Geriatrics at the University of Iceland School of Medicine. He has served on several committees for the Ministry of Health, including the IceRAI committee; he is also on the board of interRAI. He is currently involved in several research groups, including the AGES study, which is a cooperative study on healthy aging between the Icelandic Heart Association and the U.S. National Institute of Aging.

Hrafn Pálsson is the Chief of Elderly Affairs at the Ministry of Health in Iceland, where he is the director of a special fund within the ministry to improve the conditions and care of the elderly. He holds an MSW degree from Adelphi University in New York. He has promoted the use of systematic and electronic documentation of elderly assessment in various health care settings, including the Nursing Home Preadmission Assessment.

#### **ISRAEL**

Jacob Gindin is a physician with a specialty in internal medicine and geriatrics. He heads the Geriatric Institute for Education and Research at the Kaplan Medical Center in Rehovot, and is the chair of the center's geriatrics departments. Among his present activities are Head of the master's degree program in gerontology for physicians at Haifa University, and member of the Israel Geriatrics National Council. He was previously a member of the board of the Israel Geriatrics Society (1992–2002) and Director of the Department of Institutional Services for the Aged in the Ministry of Health (1995–99). In 2003 he was nominated member of the steering committee of the World Health Forum.

Sara Levi is the chief national geriatric nurse at the Israel Ministry of Health, Geriatrics Division. Her work focuses on policy, establishing geriatric nursing standards of care, professional

development, and creation of professional tools such as functional assessment for the elderly, quality assurance, and assessment of elderly abuse. Prior to that, she was the Director and Associate Dean of the Hadassah-Hebrew University School of Nursing. She received her PhD from the University of Pennsylvania, her MA at Hunter College in New York, and her BA at Tel Aviv University.

Orna Intrator, an applied statistician and health services researcher, is an Assistant Professor (Research) at the Center for Gerontology and Health Care Research at Brown University in the United States. She studies health care utilization of older adults residing in nursing homes, especially hospitalizations, with particular emphasis on the effects of nursing home organizational structure and market and public policies. She utilizes state-of-the-art statistical methods such as Markov Chain Monte Carlo estimation of multilevel models, and has been developing methods to jointly study different service utilization in models that use informative censoring due to death. She has been developing research of Israeli older adult populations in nursing homes and receiving ADL assistance at home using MDS instruments.

Jochanan Stessman currently serves as Director General of the National Insurance Institute, the Israeli social security organization, on leave from his position as Chairman of the Department of Rehabilitation and Geriatric Medicine at Mt. Scopus Hadassah University Hospital in Jerusalem. He received his MD from the Hebrew University's Hadassah Medical School in Jerusalem in 1973, and is a specialist in internal medicine and geriatric medicine. He established many of the geriatric services in Jerusalem in both general and geriatric hospitals as well as in the community, such as home hospitalization and geriatric assessment units. He is also an associate professor in the Hebrew University Hadassah Medical School (clinical) and is the head of the Jerusalem Longitudinal Study, a major epidemiological geriatric study.

## **ITALY**

Roberto Bernabei is Professor of Internal Medicine and Geriatrics at the Catholic University School of Medicine in Rome and Chief of the Geriatric Day Hospital and outpatient clinics at the Centro Medicina dell' Invecchiamento of the "A. Gemelli" University Hospital. He is the Executive Vice-President of *interRAI*. As a member of the Consiglio Superiore di Sanità, the Italian advisory committee to the Ministry of Health, he is currently serving on several national committees including those on Alzheimer's disease and on disability. He is the coordinator of the AD HOC Project, a research funded by the Fifth EU Framework Programme with the aim of identifying the best model for home care.

Marina Panfilo is Regional Healthcare Manager for Pfizer Italy. In the last ten years she dealt with public health systems in Italy as well as elsewhere in Europe. She was responsible for value-added programs to support health authorities and local health care providers in managing health care services to improve quality. Among the projects she has launched and coordinated for Pfizer is the Silvernet project: in cooperation with *interRAI* and the Catholic University of Rome, Silvernet aims to educate operators in the use of multidimensional assessment tools in elderly care.

Giuseppe Panio served as Director General of the Venosa National Health System's Health Agency between 1993 and 2000 and is presently administrative director of the Vibo Valentia Health Agency. He has taught health law at the Bari School of Nursing for the past 20 years.

#### **JAPAN**

Naoki Ikegami is Professor and Chair of the Department of Health Policy and Management at the Keio University School of Medicine, from which he received his MD and PhD. He also received an MA in health services studies with distinction from Leeds University (UK). During 1990–91, he was a visiting professor at the University of Pennsylvania's Wharton School and Medical School, and has continued to be a Senior Fellow at Wharton. He has been a board member of *interRAI* since its formation. In Japan, he is Chair of the Japan *interRAI* Committee and President of the Japan MDS Society.

Masanori Nishiyama is Director of the Medical Economics Division, Health Insurance Bureau, Ministry of Health, Labor and Welfare. He has served various posts within the ministry, including Director of the Division of Health for the Elderly at the time of the implementation of the public long-term care insurance. He received his MD in 1997 from Keio University.

#### **SPAIN**

Elaine Duncan is Research, Management, and Community Program Coordinator in the Health and Social Care Coordination Program for the Galician Ministry of Health in northwest Spain. Originally a family physician and a member of the Royal College of General Practitioners (UK), she has worked in the field of elderly care at both a clinical and management level and holds a master's degree in health promotion. She teaches postgraduate courses throughout Spain in the field of geriatric assessment and information systems for the long-term care sector and undertakes applied research in the field of community care.

Enrique Castellón is currently an independent consultant. He trained both as a physician and an economist and undertook postgraduate studies in health policy in the United States. His professional experience encompasses many aspects of the health policy and health management arena. He has held a number of key positions in Spain, including General Director of the Clinical Division of the Galician Health Service and Deputy Minister of Health for Spain.

#### **UNITED KINGDOM**

Iain Carpenter is Reader and Associate Director (older people) at the Centre for Health Services Studies at the University of Kent, Senior Lecturer in Health Care of the Elderly, GKT School of Medicine and Dentistry, and Consultant Physician at the East Kent Hospitals NHS Trust. Until 1995 a full-time NHS geriatrician, his research has included screening the elderly in the community, case-mix

for elderly, and evaluation of services for older people in acute care, long-term care, community care, and intermediate care (see <http://www.ukc.ac.uk/CHSS>).

David Challis is Professor of Community Care Research and Director of the PSSRU at the University of Manchester. The PSSRU has long-term funding from the Central Policy Divisions of the Department of Health in England. The programs of work include integration of health and social care, assessment of older people, coordinated care, and care management. This work has been influential in shaping government policy in community-based and long-term care (see <http://www.pssru.man.ac.uk>).

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